

‘WE WRAPPED HIM IN COTTON WOOL’

A QUALITATIVE STUDY EXAMINING THE
HEALTHCARE EXPERIENCE OF PARENTS
FOLLOWING THE BURN OR SCALD OF
THEIR CHILD; AND THE EFFECT OF THE
INJURY ON THE FAMILY.

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ABSTRACT

Childhood injury affects many families in the United Kingdom. In particular, burn injury can have a devastating effect, and disproportionately affects preschool children. In 2005, 158 children under five in Scotland were burned or scalded severely enough to require treatment as inpatients (ISD Scotland 2006). The aim of this thesis is to examine the impact of childhood burn injury on the family, and the parents' view of its effect on the long-term parent-child relationship, whilst gaining an understanding of the views, opinions and feelings about the healthcare experience of parents after serious burn injury to their child. From an area in the central belt of Scotland, a group of nine families of children who had been burn injured while less than five years of age were recruited. Thirteen parents were interviewed using a semi-structured interviewing technique. The study utilised a qualitative research method, interpretive description, to obtain and analyse rich descriptions of the reality of caring for a burn injured child.

Parents' feelings and opinions about the impact of the injury on long term family relationships were analysed to reveal that parents go through a process of adjustment and adaptation to parenting a burn injured child. This process has 3 stages, the first, 'holding' was recognised when parents described an overwhelming obligation to hold and be close to their child. The second, 'guarding' was identified as the parents' imperative to keep their child away from further danger and to regain their feeling of competence lost when the child was injured. The third stage, 'defending' has two elements; parental efforts to defend the child and family from shame at the appearance of the burn injury, and defending the child from becoming a burn injury victim.

This study contributes to the research on childhood burn injury by identifying a process for parental adaptation, especially in view of the long term physical and psychological effects of burn injury scarring. The implication of the parental adaptation process is that health professionals need to be able to support and facilitate parents at each stage of adaptation; helping parents to be close to their child in particular at the time of treatment, regain their feelings of lost competence by keeping the child safe, and come to terms with the reality of their child's burn injury scarring and the effects of this on their future. As the treatment and outcomes for burn injury survivors continues to improve, understanding the needs of the family in adjusting to living with a burn injured child becomes ever more important in the development of effective professional practice.

DECLARATION

I hereby declare that this thesis has been composed by myself, the research on which it reports is my own work and the work has not been submitted for any other degree or professional qualification

Helen Yewdall

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CHAPTER 1

INTRODUCTION

'The child is burned! I never hear that announcement without a shudder, for it has opened the portals to a long avenue of pain and distress, an avenue that may lead to an age-long disfigurement, and too often, by shorter ways, to the tragedy of death' (Fraser 1927).

There have been many medical advances in the treatment of burns and scalds since Sir John Fraser wrote the above in the British Medical Journal in 1927, and for the majority of burn injured children the outcomes are very good. However, parents whose children have experienced burn injury continue to suffer pain and distress as they watch their children receive treatment for what remain serious and possibly life threatening injuries (Lee and Herndon 2007).

Treating child patients in the context of the wider family has been seen as a cornerstone of acute paediatric health strategy, and is at the basis of health visiting policy (Corlett and Twycross 2006, Jack et al 2005, Coyne 1996, Caty et al 1989). Therefore, research on the impact of burn injury on the family, and how the quality of the healthcare received affects this experience is vital to our understanding of how services to this small but important group are provided.

A study of childhood injury can also make an important contribution to the wider debate on child safety, especially in the context of growing contemporary media concern on the vulnerability of the child and the responsibility of parents to ensure that they are supervised and kept away from danger. The impact of burn injury on parents, and their associated worries about scarring and longer-term health concerns,

ensures that burn injury continues to be seen as a significant challenge to the parent's perceived ability to care constantly for their child.

1.1 Background to the research

Childhood injury affects many families in the United Kingdom. For some parents it will lead to the loss of a child; unintentional injury is one of the main causes of death in children under 15 in Scotland (ISD Scotland 2006). For two million children a year in the United Kingdom, the injury will mean hospital treatment with associated stress experienced both by the child and their parents (Child Accident Prevention Trust 2002).

Although small numbers of children are admitted to hospital with burn injury, these injuries are likely to have a lasting effect, and disproportionately affect children under five. In 2005, over 200 children in Scotland were burned or scalded severely enough to require treatment as inpatients, of these 158 were under five (ISD Scotland 2006).

In a culture where there is increasing media concern about the safety of children outside the home, parents feel a strong responsibility to ensure that the child is protected from perceived external dangers (Guldberg 2007). However, statistics demonstrate that, at least for children under five, the risk from unintentional injury is much greater in the home (ISD Scotland 2006).

As the main carer for the pre-school child is generally the mother, father or close family member, it is natural that parents and professionals feel that the onus is on these individuals to protect the child. If burn injury occurs, and professional healthcare involvement is required, parents and carers can feel an acute sense of failure (Raver et al 1999, Roberts et al 1995). This may be exacerbated by raised sensitivity to professional criticism, strengthening the feelings of guilt that the parents may already be experiencing (Gaffney 2000, Jeffery et al 2000).

This thesis arose directly from an injury prevention project, which was funded by the Innovation Fund for Children's Services and coordinated by the author. The aim of the project was to try to reduce the concerning number of home injuries, including burn injury, occurring to children under five in the local area. It became evident to me, as a health visitor, that in order to gain a fuller picture of the impact of burn injury, and to understand fully how health professionals might most effectively support the family, it was necessary to understand the psychological and social effects of injury. The study aim was therefore formulated both to examine the impact on the family, but also to assess the importance of effective care and support from health care professionals, in particular health visitors. The results from examination of this aim are intended to contribute to nursing knowledge in helping to establish how staff can help families adjust and recover from the trauma of burn injury.

1.2 Aim of the study

It is evident from existing literature that burn injury experience has a significant effect and long lasting impact on the family, in particular on the parents (Watkins et al 1996). It is vital that the parents are able to offer their child the care and support that is such an important part of the trauma recovery process (Blakeney et al 1993a); however the majority of these families are likely to need help in order to adjust to the reality of parenting a burn injured child. In order to be fully effective, support for these families needs to be offered with a thorough understanding of the adjustment process parents need to go through in order to cope with the possible changes in their relationship with their child.

There have been a number of studies in the past that have looked at the effect of burn injury on the family, which discovered that the experience of injury changed the family dynamic (Landolt et al 2002, Meyer et al 1994, Blakeney et al 1990). However, there does not appear to have been a detailed investigation of the process that the parents have gone through as they have lived through the experience of having a burn injured child or how the parenting experience has been affected. The first part of the research aim has been to explore this process.

Some of the literature surrounding the immediate experience of parents has been concerned with the healthcare experience of these families (Thompson et al 1999, Heptinstall 1996, Watkins et al 1996). The attitude and actions of the professionals encountered by the family appear to be crucial to help the parents to cope, recover

and continue parenting effectively (Melnik and Feinstein 2001). Societal emphasis on the role of parents to prevent injury occurring may affect the attitude of the healthcare professionals, and there is a need to explore in detail how the approach of nurses and doctors both during and after hospital admission contribute to the recovery of the parents and child from the often traumatic experiences of burn injury. This is the second part of the research aim.

1.3 Methodology

A qualitative research design was developed to obtain detailed descriptions of the lived experience of parents with burn-injured children. Data collection involved semi-structured interviewing of a sample of nine families whose child had been seriously burned. The theoretical framework I used for analysis of the data was interpretive description, an approach well suited to a research paradigm that accepts that the health and illness experience is by its nature constructed and contextual, but which also allows for individual feelings and events to be accepted as truths (Thorne 1997).

1.4 Outline of the thesis

Following this introductory chapter, I review the existing literature in Chapter 2. In this chapter I aim to present an overview of the literature surrounding the aetiology of burn and scald injury and the effect on the family. There is also an overview of

the considerable body of literature on the socio-economic predictors of burn injury and the effect of family circumstances on safety practices.

In the review I then consider the role of professionals in injury prevention and the aftercare of families following injury. The following section is concerned with the experience of parents during the hospital attendance of their child. There is also reference made to the research around the longer-term psychological effects of the injury on both the parents and child.

In Chapter 3 I describe the method used to conduct the study and provide a justification for the use of a qualitative approach, and interpretive description in particular. In this chapter I give a detailed account of the conduct of the study, including ethical issues.

In the first part of Chapter 4 I introduce the parenting themes identified through analysis of my data, and discuss the development of the parental adaptation model proposed in this work. In the second part of this chapter and the following chapters 5 and 6, I present a detailed analysis of the three parental adaptation process themes with reference to relevant literature.

In Chapter 7 I present the findings of the research in relation to the healthcare experience of parents, in particular their views and opinions on what happened while their child was in hospital.

Chapter 8 draws together my examination of the impact of childhood burn injury on the family and the healthcare experience of parents. My objective in bringing the analysis of the two sets of themes together is to develop knowledge on how professionals can more effectively help and support the parents of burn injured children through the parental adaptation process, resulting in a successful adjustment to changes in family life.

In the final chapter I conclude on the implications of the findings on current practice, and recommendations made for further research.

Chapter 2

LITERATURE REVIEW

2.1 Introduction

This review considers the literature surrounding the incidence of burn injury, and the effect on the family. There is an overview of the considerable body of literature on the socio-economic predictors of burn injury and the relationship between knowledge, family circumstances and safety practices.

The review then considers the role of professionals in injury prevention and the aftercare of families following injury. An examination is carried out on the position of health visitors in particular, and research is contrasted on the attitudes held by health visitors on their role, and the opinions of clients.

Finally the experience of parents during the hospital attendance of their child is considered. There is also reference made to the research around the longer-term psychological effects of the injury on both the parents and child, with a review on the literature surrounding the phenomenon of parental guilt following accidental injury. The effects of the injury on the family are also considered.

2.2 Search strategy

In order to identify the context of the research, a broad literature search was carried out using OVID databases, including MEDLINE, CINAHL and psycINFO using the

key words 'childhood injury' and 'injury prevention'. Once burn injury had been identified as the area of specific interest, a more specific search was carried out using the same databases, and with the key words 'child burn injury' and 'parents and burn injury'. The date parameters used for the electronic search throughout the research process were 1995 to 2008. Only papers originally published in the English language were included.

Electronic searches were complemented by examination of the reference lists included in the electronically sourced papers, as well as research found by manual searching of relevant specialist journals held in the university and hospital libraries. In addition, the adoption of interpretive description as a research method allowed the use of the considerable body of lay print and media information in relation to childhood burn injury to be utilised as background reading during the literature search (Thorne et al 1997). This was of particular importance in the later stages of the research process, as it allowed testing of the developing theory of parental adaptation in relation to prevailing culture.

2.3 The epidemiology of burn injury

Burn injury has long been recognised as a significant contributor to mortality and morbidity in young children (Fraser 1927). As can be seen from the quotation in the introduction to this thesis, severe burn injury has always been seen as potentially disastrous for the health and development of the child. Eighty years later, authors still recognise the overwhelming physiological and psychological challenges produced by

burn injury in children, and the unique problems that the burn injured child poses for even the most highly trained and experienced professional (Lee and Herndon 2007).

Recent figures reveal that in 2005, over 200 children in Scotland were burned or scalded severely enough to require treatment as hospital inpatients, of these 158 were under five (ISD Scotland 2006). Research indicates that children under five suffer nearly forty-five percent of all severe burn and scald accidents in the United Kingdom (DTI 1999). Children in this age group are recognised to be particularly at risk due to their relatively small body area, the sensitivity of young skin, and their vulnerable physical position in relation to hot objects (DTI 1999).

Statistics collected on hospital admissions indicate that cups or mugs containing hot liquids account for the largest single cause of burn injury (37%), and the key location for the accident is the kitchen (DTI 1999).

Sustaining a severe burn injury is one of the most traumatic accidents a child can experience (Landolt et al 2002). It usually requires treatment in a specialist burn centre (Jeffery et al 2000); the child may require formal resuscitation and skin grafting (Feldman et al 1998) and will certainly need long-term treatment as an outpatient (Jenkins and Stanwick 1991). Scarring from the injury is likely to cause physical and psychological problems both for the child and the family (Blakeney et al 1990, Meyer et al 1994).

Considering, therefore, the potential seriousness of burns and the devastating effects they can have on the child and on the family, it is unsurprising that a significant amount of literature has been devoted to the prevention of this type of injury. Much of this literature surrounding burn injury prevention is concerned with the predictors of injury, mainly in order to target educational and environmental measures. The next part of this review is concerned with the research that has been carried out on those children and families most at risk.

2.4 Socio-economic and psychosocial predictors in accidental injury and safety practices.

A considerable amount of research has been undertaken on the connection between social circumstances and injury. Some of the studies conducted have examined injuries in general, but there are a number that have focused on burn injury specifically.

The greatest body of evidence is concerned with the association between socio-economic circumstances and a higher risk of any injury. Alwash and McCarthy (1998) examined the link between social and economic disadvantage and raised injury risk. In a quantitative study of children (n=402) attending Accident and Emergency following home injury in West London, it was found that although there was no significant difference in attendance among ethnic groups, standardisation of accident rates revealed a strong gradient by social class. There were also significant associations with maternal unemployment, overcrowding and residence in social

housing. The authors also identified that the children of working class families experienced injuries of greater severity, but stated that the nature of the study examining hospital attendance excluded more trivial injuries. This may have had the effect of over-representing the proportion of severe injuries experienced by families in lower socio-economic groups

Other efforts have been made to examine links between ethnic background and burn injury risk. Quayle et al (2000) collected demographic data in a retrospective review of over eight thousand children treated for burn injury in Missouri hospitals during 1994 and 1995. Sixty-four percent of the study group were children under five. Results indicated that African-American children were at increased risk of injury, particularly if living in a deprived area. Lack of detail within the data made accurate analysis of the socio-economic reasons for these results impossible; however the study findings were supported by Delgado et al (2002). These authors found strong associations between burn injury, poverty, poor maternal education and overcrowding. In this case, the authors were able to give a detailed description of the specific environmental reasons for many of the injuries, which took place in an underdeveloped area of Peru. It could be questioned how transferable the results of this study are to developed countries, however the research study does give valuable insights into the influence of the home environment on burn injury risk.

It might be surmised that intrinsic family characteristics have an influence on injury risk, and some authors have made efforts to explore further precisely what factors within a household might explain the greater injury risk. In a longitudinal,

prospective study of ten thousand families in the Avon area carried out by O'Connor et al (2000), the authors identified that children at two years of age were significantly more likely to have experienced burn or scald injury if living in a single parent or step-family. However, after controlling for the social class indicators of overcrowding, poverty and lack of educational achievement, the difference was negligible. This seems to suggest that the likelihood that lone parent households will experience poor housing and poverty is more significant for injury risk and more relevant than the number of adults living in the home.

The influence of poverty has been examined by other research, in particular by Edwards et al (2006) and Roberts and Pless (1995). These authors have sought to establish why families living in areas of deprivation and on a low income are more likely to experience injury. They directly link lack of employment to injury risk. Edwards et al (2006) established that although deaths from injury have reduced significantly in the past twenty years, the death rate of children of parents who have never worked, or who are experiencing long term unemployment is thirteen times higher than the death rate of children whose parents are in higher managerial or professional occupations. The authors suggest that poor, overcrowded and unsuitable housing may be one of the factors influencing injury rates.

Roberts and Pless (1995) carried out further research on the link between maternal unemployment and increased risk of accidental injury. In a paper encouraging debate on the effect of social policy on lone parenthood, the authors quote a number of studies indicating lone parenthood as a strong demographic predictor of injury.

Again, they argue that the association is most likely to be explained by poor housing linked with poverty and social isolation. The authors use this evidence to suggest that an increase in day-care provision would lead to opportunities for employment for parents, and therefore improve housing conditions and reduce social isolation.

The influence of poor housing in relation to childhood injury has been explored in greater detail by Mott (1999), who attempted to assess the independent associations between home environment, behavioural and socio-demographic risk factors, and children's medically attended home injuries. The researcher used data from the National Longitudinal Survey of Youth, which involves a large sample of participants (n=12,000) and was funded by the United States Department of Labor. The survey contains maternal reports of medical attendance, as well as interviewer observations of the home environment. The results indicated that children coming from homes described as dark and cluttered by observers were significantly more likely to have had a reported home injury.

If, therefore, we bring together the findings of some researchers, indicating that childhood injury risk is heightened in cluttered homes, with the findings of others that poverty and unemployment is more likely to result in poor, overcrowded homes, the link between disadvantage and injury appears to be clearer. However, environmental influences do not fully explain how and why childhood injury occurs.

In order to gain a clearer picture of factors influencing injury risk, it is important to explore fully the other issues affecting the ability of parents to keep their child safe in

the home. The birth of a baby awakens in the parent an instinct to protect the child (Dally 1982); it could be argued that this is achieved by developing behaviours aimed at keeping the child safe from danger at all times. It is the influence of external factors on the development of these behaviours that is considered next.

2.5 Influences on parental safety behaviours

There is considerable literature reporting research on the development of parents' safety behaviours. A significant part of this discusses the difference between safety practices carried out as a result of 'common sense', those taught by intentional education, and those learnt as a result of experience.

2.5.1 Instinctive safety practices

Keeping children away from danger is seen by many as a matter of instinct or 'common sense' (Haycock-Stuart 1999, Dally 1982). If this is accepted, it could therefore be assumed that parents have an instinctive and intrinsic awareness of what is likely to be hazardous to their child, and will therefore take steps to anticipate dangerous situations. Although a number of studies have looked at the development of safety practices (Hilton 2002, Hu et al 1996, Morrongiello and Dayler 1996, Roberts et al 1995, Combes 1991) the authors have not selected their study sample to compare the responses of first time parents with those with more than one child. This makes it more difficult to assess if reported safety awareness has resulted from greater parental knowledge and experience. However, in a study looking at differing

attitudes to injury prevention measures according to whether participants were first time parents or had a number of children, Vladutiu et al (2006) found that first time parents with young babies in the study sample (n=594) did not tend to demonstrate awareness that injury prevention measures were an integral part of parenting. This would seem to suggest, at least for these parents, that injury prevention was not an instinctive part of caring for their children.

2.5.2 Knowledge-based safety practices

If, despite the instinct to protect the child, injury prevention awareness is not intrinsic to parenting, it may follow that parents need to be educated about hazards in order to increase parental understanding of risk to their children. Some authors have attempted to assess the effectiveness of taught safety education messages in the day-to-day care of children. A good overview of the efficacy of interventions can be gained by examining systematic reviews of a range of injury prevention strategies.

In the third of four systematic reviews of health promotion interventions aimed at reducing unintentional injury, Towner and Dowswell (2002) looked at ten international studies reporting on community based injury prevention programmes. The authors reported on the target group for the intervention, aims, content and key results. The overall outcome of the interventions was reported, and the strength of the evidence provided by the study findings was assessed. Out of the ten studies, all of which involved education of parents and or children as part of their programme, none were judged to have been fully effective and only five were partially effective.

The remaining studies were considered to be either inconclusive or ineffective. The authors conclude that the strongest programmes incorporated a range of interventions, including community involvement, multi-agency partnership working and environmental adjustments. In general, those involving educational interventions alone appeared to be less effective at reducing injury incidence.

However, some of the programmes did report success if educational interventions concentrated on one or two specific injury risks, for example burns and scalds or poisoning, that could be reduced in the home environment with minimal effort. This may suggest that unless parents are given specific achievable measures that they can take, simply raising awareness that children are at risk of injury results in very little behavioural change.

These findings were supported by Hu et al (1996), who conducted a survey using a random-digit telephone dialling technique. A structured questionnaire was administered to a group of parents of at least one child under fourteen (n=1500). Questions were asked about the participant's knowledge and attitude to child safety, as well as about selected safety practices such as reducing hot water temperature. Results indicated that injury prevention practices were more likely to be associated with specific knowledge on childhood injury than with actual concerns that their own children might be vulnerable to injury. Chi-square tests used to analyse differences among sub-groups indicated that this was applicable regardless of educational attainment or family income. The findings of this research seem to indicate that

safety education should concentrate on specific injury risk, rather than depending on parental concern about their own child's safety.

The reasons behind the adoption of safety practices is an area of interest to injury prevention professionals, as it can help determine the most effective means of education. Morrongiello and Dayler (1996) undertook research in Canada to examine attitudes, awareness and beliefs regarding injury risk. A variety of methods were used, with a broad sample group of parents (n= 113) from a variety of socio-economic groups most with children under four. A focus group format was used to test a number of scenarios about child safety situations. For each scenario parents were asked to identify the potential injury, identify alternatives to the action taken by the caregiver in the scenario and asked to give an explanation for what the parent did. Content analysis was carried out on half the responses in order to identify commonalities. There were a number of interesting results from this research.

When asked about the thoughts of the caregiver, uniformly elicited responses indicated that the parents did not routinely think in terms of injury possibilities, and although they appeared knowledgeable about injury risk, these were often not identified until the researchers drew attention to them. In general, parents were able to suggest alternative safety behaviours to those in the scenarios but said that in the same situation, they would have acted in the same way as the fictional caregiver.

The authors documented five categories of reasons for safety behaviours as suggested by parents:

- Issues of convenience – it was easier to allow a potentially risky situation than to change it.
- Minimising confrontation – stress on the main caregiver was often high, resulting in a willingness to allow the child to do what they wished to avoid conflict.
- Priority of own goals – the pressure to carry out a given task was greater than the need to ensure a safety routine was carried out.
- Under or overestimating child's ability – belief that the child was not capable of a risky behaviour, or conversely that they were able to manage the risk themselves.
- False sense of security – the child had engaged in the risky behaviour before and the parents had managed to keep them safe.

Another interesting discovery was that 74% of the parents questioned strongly believed that children naturally behaved in a way that inevitably led to injury, and 82% believed that getting injured was an expected consequence of children playing. This is particularly pertinent when it is considered that most of the sample group had children under four, when increased protectiveness might be expected. It also suggests that this group of parents felt that accidents were bound to happen.

The authors conclude from their findings that parents do not routinely feel the need to engage in injury prevention practices unless motivated by an injury or near injury to their child or another child they knew. They described these as reactive preventative actions rather than pro-active or anticipatory actions. This therefore

suggests that safety education messages may be less effective at changing behaviour than experience of injury.

2.5.3. Learning from experience of injury

The findings of Morrongiello and Dayler (1996) have been corroborated by a quantitative study using a sample of parents in East Dunbartonshire (n=66). Hilton (2002) noted that half of the group (n=39) were most influenced to make safety changes in the home by hearing about accidents.

In a study for the Child Accident Prevention Trust, Combes (1991:26) noted the responses of parents (n=112) in focus group discussions during a small qualitative action research project. Parents identified accidents and near misses as an important learning experience:

‘Sometimes it takes an accident - then you’re wise after the event.’

Roberts et al (1995:84) also noted this response during very detailed and well-structured parental interviews following twelve near accidents located in a district of Glasgow. The participants revealed that incidents they heard about in the local area helped them prevent future accidents:

‘Everything like this does make you a bit more cautious; a bit more aware to check things...That is how your safety awareness develops, by things which nearly happen, just managing to avert them.’

These interviews were carried out as part of a much larger investigation of childhood injury risk and safety behaviour carried out in a very deprived area of Glasgow. As

well as interviewing parents, the researchers used focus groups with professionals and parents to increase the strength of their findings.

The concept of learning safety behaviours through experience appears to be supported by Johnson et al (2000). On examination of the post-injury admissions of a very large cohort of children (n=41242) between 0-15 years of age, there was an apparent reduction in injury risk to a child less than one year of age after exposure of a sibling to accidental injury. It is tempting to hypothesise that the incidence of an accident increases parental vigilance; however the authors state that it is difficult to interpret this observation without detailed accident histories, which would clearly have been impossible with a study cohort of this size. However, the strength of the finding is greatly enhanced by the size of the sample suggesting the reduction in the injury rate is unlikely to be merely coincidental.

2.5.4 Social factors affecting safety practices

As well as parental knowledge, it is also important to assess how socio-economic factors affect safety practices. There is some evidence that disadvantaged families display more unsafe practices than financially affluent families (Hapgood et al 2000). In a study designed to explore the relationship between socio-demographic variables and safety practices, responses to questionnaires completed by one thousand five hundred and ninety four families in the Nottingham area were analysed. Results were collated in terms of an overall safe practice score, and also for practices requiring use of safety equipment. The authors argued that previous evidence suggested safety

equipment ownership might reasonably be affected by low family income but it was more difficult to prove whether economic factors affected behavioural safety practices. The authors found a link between socio-economic disadvantage and a low level of equipment utilising safety practices, but concluded that there was insufficient evidence from the results to conclude that disadvantage led to poorer safety practices in general. They did, however, find a link between ethnicity and low ownership of safety equipment.

Colley (1994) discovered significant differences in safety knowledge related to social class. In a small quantitative study involving twenty-six families with children aged eighteen to twenty months, Chi-square test analysis of questionnaire results showed definite social class differences in levels of safety knowledge and ownership of safety equipment. The author speculates that cultural differences may limit access to information on safety, and environmental differences may limit the time parents give to safety issues. However, the study is insufficiently detailed to provide evidence for these explanations.

2.5.5 Family functioning and burn injury

The studies reviewed seem to provide evidence suggesting how the safety practices of parents may be affected by past experience or knowledge, but another important influence may be the dynamics of the family. It has been argued that the links between childhood burn injury, poverty, and lack of social support are likely to be explained by severe stress or dysfunction within a family. Kendall-Grove et al (1998)

examined a sample group of one hundred and eleven families attending a large urban burns centre in America. They found that 36% of the families exhibited at least one type of parental dysfunction (a history of substance abuse, current or past involvement with child protection services, imprisonment or psychiatric history). The authors state that their study included a wider range of psychosocial indicators for family disturbance than previous studies, extending the premise that burn injury should be regarded as a symptom rather than a cause of problems in the family. Stoddard and Saxe (2001) in a ten-year review of childhood injury literature also conclude that there is evidence that difficulties within the family place children at higher risk of burn injury.

In contrast, Blakeney et al (1993a) examined a group of families (n=120) and concluded that stress was not an etiological factor in the burn injury. However, they admit a limitation of this study was that they failed to determine if parents were feeling more stressed after the injury than before, and suggest that this might have been a reflection of the Parental Stress Index used, as this assesses multiple stress factors rather than those specifically arising from the burn injury.

There is also evidence that maternal depression may have an influence on injury risk, although not specifically associated with burn injury. MacLennan and Kotelchuck (2000) examined the maternal self-report components of two linked national databases in Canada. The sample group involved a large number of mothers (n=7500). Using weighted bivariate and multivariate logistic analyses the authors assessed the relationship between maternal depressive symptoms and self reported

parental injury prevention practices (plug cover use, ownership of ipecac, and utilisation of car seats). The results indicated that engagement in prevention practices was less likely if the mother reported high levels of depressive symptoms when their children were two, and again at three years of age. The authors speculated that the depressed mother might underestimate her engagement in safety practices as part of a general devaluation of her parenting abilities, but were unable to test this hypothesis with the available data. It might be argued that the specific nature of the prevention practices identified in the study makes this hypothesis unlikely.

It can therefore be seen that the parents' ability to keep their child safe is affected by a myriad of factors; they need to know that their child may be at risk and how to prevent injury, and they also need the means to protect the child from a dangerous environment. However, it is also evident that in some families the ability to protect the child from injury may be seriously affected by mental health problems, stress and poverty. In these cases, the support and help of health professionals is likely to be crucial. The next part of this literature review discusses the role of health visitors in safety education, and in supporting the parents of children experiencing injury.

2.6 The role of health visiting in pre and post accident safety education

It is widely understood that the primary health care team and health visitors in particular, have a prominent role in childhood injury prevention and support (Roberts et al 1995, Kendrick et al 1999, Kendrick et al 1995, Carter et al 1995). Traditionally health visitors have provided a universal service to families with young children; it

seems therefore that health visitors are likely to be the professionals with the largest influence on the safety behaviours of parents. Available literature suggests that the health visitor role in injury prevention should have two elements, pro-active and reactive. The pro-active role can be seen where health visitors provide information or equipment to help parents to keep their child safe; reactive involvement is appropriate following the injury episode when the health visitor may provide family support and advice to prevent further injuries.

Much of the research that has been conducted in this area is concerned with the opinion held by both health visitors and parents of the pro-active role. In a recent study Hilton (2002) explored the perception of health visitors of their health promotion contribution to childhood safety in the home. A sample group of fourteen health visitors were interviewed on the role they felt they filled in home accident prevention. Results indicated the health visitors in the study group all felt that they played a central role in safety education. However, when questioned about the effectiveness of their role, half of the group (n=8) felt a sense of failure due to the constraints of the system in which they worked. Lack of time and a heavy workload was most commonly mentioned as a reason for this.

Other studies have noted similar findings on health visitor views. In a much larger quantitative study Marsh et al (1995) reported that a large number of health visitors believed that they could be effective in preventing childhood accidents, however the results reveal what was described as discrepancies between attitudes and practices of health visitors. Health visitors (n=186) returned questionnaires partly aimed at

gathering data on attitudes to accident prevention work. Results revealed 74% of respondents agreed that health visitors should campaign on local safety issues but only 22% did so; 71% agreed that post-accident visits were important, but only 61% carried out such visits. The authors suggest that this discrepancy may be due to health visitors experiencing barriers in undertaking accident prevention work; however the study was not intended to address what the barriers might be.

A similar study by Carter et al (1992) in North Staffordshire considered some of these issues. A study sample of health visitors (n=89) replied to an eight-page questionnaire designed to gather quantitative information on caseload, attitude to child accident prevention work and knowledge on injury prevention. Results revealed that although all participants undertook some accident prevention work, only 12% felt that they did enough. The most commonly mentioned reason for this was lack of time (46%). Other reasons mentioned were lack of teaching materials, pressure of caseload, covering vacant posts and lack of clerical support.

2.6.1 Client views of health visitor role in accident prevention

It is interesting to contrast the opinion expressed by health visitors of their remit for accident prevention, with the perception of that role expressed by the clients. Hilton (2002) studied the response to questionnaires returned by parents (n=66). Although parents in the study group did identify health visitors as the most important professional source of home safety advice, other sources such as friends, family and childcare books were more frequently cited. In addition, Combes (1991) found that

the majority of parents involved in the focus groups in their study (n= 112) did not recall having talked about safety with the health visitor at all.

It is informative to explore what parents think of the health visitor's role in injury prevention. Combes (1991) found that parents identified their own safety needs as wanting information on safety equipment, advice on making the home safer, and help with first aid skills. The author identified that if parents felt these needs were met, they were more likely to listen to the advice given by professionals. In the study of health visitors in North Staffordshire, Carter et al (1992) found that 98% of the health visitors in the group would recommend safety equipment. Although 88% considered that the most commonly considered reason for parents not acquiring the equipment was financial, only 30% of the group had applied to Social Security on behalf of clients. It is possible that this apparently low percentage may be a reflection of local knowledge on social security budgets rather than actual need, but the authors did not confirm this. The study also does not include the views of parents leading to the suggestion that there may be a mismatch between the perceived and actual needs of clients for safety equipment.

In their detailed study of childhood injury in an area of Glasgow, Roberts et al (1995:90) quote parents who feel professionals simply get it wrong:

'Ah feel sometimes that some of the health visitors don't have a clue what they're talking about. I mean quite honestly, because they havnae really handled a situation...sometimes they tell you practical stuff...you know, it isn't practical'

This quotation seems to indicate that there is an inherent gap between what health professionals consider to be practical measures to improve home safety, and what

parents feel are achievable within their resources. Arguably, this gap could be closed by the availability of free safety equipment, for example stair gates and fireguards, which provide a physical means of preventing childhood injury (Thompson et al 1998). However, Roberts et al (1995) also identify that the parents in their study had been able to improvise methods of keeping their children safe by adapting existing resources. Professionals if appropriate could exploit this local knowledge.

More recently, Hilton (2002) found health visitors considered that their role was developing more widely in accident prevention work. Rather than simply taking an educational approach, they were adopting a more supportive role offering practical assistance to parents. The facilitation of low cost safety equipment schemes continues to be encouraged by a range of studies (Thompson et al 1998, Clamp and Kendrick 1998).

2.6.2 Reactive health visitor intervention

If health visitors have a vital contribution to make in the prevention of injury, they are also considered to have a major role in reactive post-accident intervention (Marsh et al 1995). Available literature, however, indicates that post-accident visiting is not always carried out. Carter et al (1992) described that 80% of health visitors in North Staffordshire received notification of attendance to A&E, but only 13% would visit all cases.

In an effort to discover how health visitors decide which families to visit after injury notification, Reynolds (1996) categorised the process of evaluation used by the individual practitioner. Analysis of the qualitative data revealed that knowing the family was an important factor in deciding to visit, as well as clinical judgement on whether the injury was to be expected given the age and developmental stage of the child. Participants also mention 'gut feeling' influencing their decision to visit, usually based on their previous knowledge of the family and the circumstances surrounding the injury.

'Gut feeling' is a phenomenon mentioned in other studies on the work of health visitors. Ling and Luker (2000) interviewed health visitors who had been involved in child protection procedures, finding that they described their actions in each case as being inspired by 'intuition' or 'intuitive awareness' that something was wrong. The authors describe the 'gut feelings' of health visitors as being informed by empathy developed by experience, as well as informed by their specialist training allowing them to give meaning to complex situations.

Reynolds (1996) identified that practitioners recognised inherent difficulties in post-injury contact because the clients were suspicious of their motives. Combes (1991) writing for the Child Accident Prevention Trust also found that parents in the research perceived these visits as negative or difficult. There were four major reasons for this:

- Parents felt that their accounts of the accident were not believed.
- They felt they were being accused of abusing their children.
- They were not told how the health visitor knew their child had been involved in an accident.
- The visit focused on the needs of the child and excluded the feelings and needs of the parents.

More positive experiences seemed to revolve around the parents already having a good relationship with the health visitor. Combes (1991) concludes that this may be because parents are more confident that previous knowledge of the family will be taken into account, and also feel more able to express personal feeling and needs.

Combes (1991) also reported that parents believed that the health visitor domiciliary service was not universal, as it was at that time, but targeted towards families in need or suspected of child abuse. The author suggests that this view may well explain an adverse reaction to a post-accident visit even before anything has even been said. Much of this reaction may be inspired by the parent's own sense of guilt that the injury has occurred, combined with a reluctance to repeat the story of the injury. It is possible that recent changes in national health visitor service provision resulting in more targeted services may make a negative parental response more likely now than at the time of the report.

Conversely, Scheidt et al (2000) undertook research on the views of parents on the perceived value or threat of interviews about their child's injury. The research was

initiated as part of a wider attempt to gain detailed information about childhood injury. In order to gather accurate histories, the parents of all children attending ten hospitals in the District of Columbia were contacted immediately following attendance and interviewed on the telephone about how the injury happened, who was supervising the child and what safety precautions were in place. The study group of parents (n= 1400) were also asked if the interview made them feel angry, offended or threatened. Results indicated that 90% were not upset or threatened by professional questioning on how their children became injured. There was also a markedly low rate of refusal to take part in the interview (2.9 %), which gives further weight to the findings.

The evidence suggests that although there is an expectation that the health visitor will provide the lead professional role in childhood injury prevention and support, in reality this role may be limited. Although the provision of a consistent, responsive and universally available service to parents concerned about safety or following an injury is considered vital, the views and opinions of professionals and parents seems to indicate that this service is limited or missing in many parts of the United Kingdom. The reasons behind this are complex, but certainly the pressure of work and the increasing role of health visitors in child protection work may have influenced the parent's perception as to whether they can expect their health visitor to offer pro-active injury prevention advice.

Research also seems to indicate the ambivalence felt by health visitors when considering post-injury interventions. The studies revealing that a relatively small

number of health visitors routinely visited following the notification of injury (Carter et al 1992), as well as the feelings expressed by the parents who had experienced this intervention (Combes 1991, Reynolds 1996) indicates there are inherent difficulties in approaching the matter of post-injury support.

2.7 The parental experience of their child's admission to hospital following burn injury

Severe burn injury results in admission to hospital for treatment. There are a number of useful studies looking at the experience of parents during an inpatient stay. Those mentioned here concentrate on the support needs of parents, the importance of staff attitude in response to the likely distress exhibited by the family, and the importance of the provision of information.

Of particular interest to this research was the work carried out by Heptinstall (1996) on behalf of the Child Accident Prevention Trust. The study aimed to determine the experiences and needs of parents and children following accidental injury. Opinions on the support offered to families by professionals were collected, and the results were used to identify practices helping to reduce emotional stress after an accident.

Questionnaires (n=5500) were sent out to parents and children attending three Accident and Emergency departments in the United Kingdom. The researcher also carried out a small number of in-depth interviews with families. Both qualitative and quantitative information was collected on family demographics, the injuries

sustained, and opinions on the support gained from emergency services and hospital staff. Data on the long-term effect of the accident on the child and the impact on the family were also gathered.

The response rate to the questionnaires was low, with a mean return rate across the hospitals of approximately 25%. Only a small proportion of the injuries reported were burns, but relevant data were collected on the experience of families attending both the Casualty department and the subsequent admission to a children's ward. The families felt a positive staff attitude, good information for parents and children and a friendly atmosphere were very important. Parents also expressed appreciation at being allowed to remain with their child at all times. More negative findings were that although very good with the child, professional attitudes to carers were often different, and staff seemed to have no time for the parent. Parents expressed a need for support and comfort for themselves, as well as measures to address practical needs. This was also reported by Combes (1991), who found parents felt health visitors specifically were failing to meet their need for support and help following their child's injury.

Healthcare professionals failing to take into account the feelings and concerns of family members is of concern when consideration is given to the importance of family support in the child's post-burn psychosocial adjustment. There are a number of research studies looking at the reactions of family members, and what they need from professionals in order to be able to support the patient after an injury.

2.7.1 The needs of family members after burn injury

Watkins et al (1996) studied the post-burn psychological adaptation of family members during the time of acute injury through to completion of recovery and rehabilitation. In order to illustrate their theory of adaptation, they present three case studies including the mother of a seven-year-old child, the husband of a female patient and the wife of a male patient. They identify four phases in adaptation: crisis, control, commitment and consequences by describing the set of issues on which the family member is concentrating, as well as the emotional and behavioural responses that the individual may demonstrate.

The first stage, crisis, is when the family member becomes aware that the patient has been injured. The authors suggest that for those actually with the patient at the time of the accident, this early stage may be characterised by the family member feeling calm or numb. This has survival value, as it allows the parent, for example, to function in a relatively normal manner in order to administer first aid and summon help. Once help is found, this calmness may disappear as the carer shifts their focus onto meeting their own needs. This may mean a simultaneous centring on the patient's condition and on establishing the carer's extent of personal responsibility for causing the injury. These feelings of confusion, anxiety and guilt may lead to the carer appearing distraught, tearful or even angry.

Determining personal responsibility for the injury is, according to the authors, vital to return to psychological equilibrium. They recommend that staff can best help this

process by providing respectful, supportive, compassionate and honest care for the family.

If this phase is not resolved, the authors state that the family member is likely to exhibit hostility towards professional caregivers, unable to trust the care of the patient to someone else when feeling they themselves let the patient down. Ensuring the 'best' care by being critical of health professionals may be seen as a way to relieve some of the family member's guilt and redeem their perceived negligence.

In the control phase, the authors describe the family member as experiencing a need for detailed information about the patient's progress, as well as making great efforts to secure practical arrangements for the rest of the family. Those who have not been able to resolve the issues of personal responsibility may exhibit overtly hostile and critical behaviour towards the professional caregiver.

In the third phase, commitment, Watkins et al (1996) describe the family members having to make a conscious effort to decide how much support he or she is willing to provide in order to help the patient to recover. The emotional reaction to this choice is inevitably affected by the quality of the relationship pre-burn injury, and also depends upon the level of optimism felt by the family member about how far the relationship can return to normal.

In the final phase, consequences, the family member is faced with the task of assessing the long-term effects that the burn injury will have on both the patient and their relationships. The family member is required to renegotiate a renewed bond

with the patient that will meet the needs of both individuals, as well as coming to terms with the economic, emotional and social effects of the burn injury.

The work of Watkins et al (1996) provides a valuable contribution to knowledge on the different stages that family members may go through in order to adjust to the reality of their loved one's burn injury. The authors present it in order to inform professionals about the reactions they may encounter when dealing with relatives. Other authors have also investigated the needs of relatives.

Thompson et al (1999) carried out a qualitative study of the needs and concerns of family members while a relative was hospitalised in a specialist burn centre in the United States. Twenty-seven family members of paediatric patients were interviewed as part of a larger study group of ninety-seven relatives of burn patients. Open-ended interview techniques were used to explore family worries and needs and identify support strategies. Qualitative data from interviews were evaluated by content analysis. The results from the paediatric patient group were then compared with those from the adult patient group. The child patient group had high levels of concern about pain, skin graft surgery and future scarring. This group also indicated a high level of support from staff for their own personal needs. The authors speculate that this may be because parents, for example, spend proportionately more time at the patient's bedside, often living in the hospital. Nurses were mentioned frequently as a major source of information, support and comfort.

Kai (1996) used semi-structured one-to-one interviews with thirty-two parents living in a disadvantaged community to collect qualitative information on their experiences and difficulties in caring for ill children. Focus group interviews were also conducted with a further sixty-two parents. Participants discussed their feelings of disempowerment and loss of control, particularly when their child had a high fever or they were fearful that they might have meningitis. In some cases, they failed to understand the means by which professionals evaluated the child's condition, and also felt confused about the treatment prescribed. Major findings in this study include a discussion on the need for specific and practical information to help parents understand their child's treatment. The author found parents felt that information should be developed according to their needs and incorporate their experience and skills.

Melnyk and Feinstein (2001) emphasised the importance of giving parents information on what to expect during and following admission to hospital. In a sample group of forty-nine mothers with a child in hospital, half were given audiotape information on the most common behavioural and emotional responses displayed by young children in hospital. The control group was given information on hospital procedures. Results indicated that the intervention group exhibited less anxiety and participated more in their children's care during their stay. As a result of improved parental coping strategies during hospitalisation, the children exhibited less post-hospital negative behavioural change.

It seems evident therefore that the experience of the time spent in hospital is of great importance to the child and the family. Even though this time may be relatively short, the attitude of the staff and the feelings that this engenders in the parents is likely to have a long term effect on the adjustment of the family to the burn injury.

2.8 Long-term effects of burn injuries within the family

Severe burn injury inevitably leads to emotional and psychological effects for all family members, as well as physical changes for the child. These consequences can be mitigated by the ability of the family to cope with the longer-term effects. There are a number of studies looking at the effect of the injury on the family; it is intended to look briefly at research on the potential effect of family dynamics on the recovery of the child, then in more depth on the effects of the injury on the family.

2.8.1. The effect of burn injury on family psychological and social wellbeing.

Rossmann and Gamble (1997) carried out a study intended to examine the understanding of children of physical injury, their emotional reaction to the injury and how they cope depending on the ability of the family to respond. Using a study sample of thirty-four children and their mothers, the researchers administered a demographic questionnaire to the parent. The aim of this was to obtain parental perceptions of the frequency of physical injury and the child's affective and coping responses in these situations. On a five-point scale, mothers were asked to indicate the extent to which they observed reactions to injury, with the child seeming upset,

looking sad or appearing angry. They were also asked to rate the extent to which they noticed their child using coping strategies; by crying, seeking parental help to a greater or lesser extent or helping themselves. Children's reactions were assessed by asking them to act out what was described as an 'injury/distress/get help story', and posing questions about the story. Results indicated that how children perceive adult reactions to their injury was critical in helping them to adjust. Given a sensitive response children can use adult assistance to calm themselves and build up understanding of the injury. In the instance when an adult caregiver is unresponsive to an injury, the child may need to use earlier comfort strategies, for example clinging or rocking, and therefore appear to regress significantly.

Blakeney et al (1990) tested a group of forty-four adolescents who had experienced very severe burns and were more than one year post-injury. A variety of methods were used including a clinical interview, intelligence tests, a family environment test, and a suicide probability scale to identify variables. Data were analysed using multiple regression designed to establish which variable might account for difference in psychological adjustment. Results indicated that those participants with a committed cohesive family environment exhibited good psychosocial adjustment following childhood burn injury. Family environment exhibiting conflict and diminished cohesion predicted poor psychosocial adjustment. This was also a finding in a very similar study in Switzerland (Landolt et al 2002), although the study investigated the views of the parents rather than the burn injury survivors themselves.

Barnum et al (1998) noted similar results. The authors examined psychosocial development of twenty-nine adolescent burn survivors in contrast to a peer comparison group. Predictors of adjustment were also considered including burn characteristics, family environment and social support. Results showed little difference between the two groups; however analysis of the findings indicated that a supportive, hopeful family environment was a significant predictor of good social adjustment for the burn survivors.

Blakeney et al (1993b) carried out a similar study of twenty-five children surviving very severe burn injury (over 80% of total body surface body area). Parents, teachers and the children were asked to complete standardised questionnaire instruments on the child's behaviour and social adjustment. Results also indicated that the children did not exhibit higher levels of adjustment problems than a reference group.

In contrast, Meyer et al (1994) found that parents of burned children completing the same standardised behaviour checklists report high levels of behavioural problems. The authors carried out a study intending to examine the relationship between these behaviours and the parent's own emotional well-being. Using a group of thirty-eight families selected using a stratified sampling technique to represent a wide range of ages, parents were asked to complete questionnaires on their children's behaviour and their own stress. Results indicate that parents saw their burned children as more demanding and exhibiting less acceptable behaviour. Their own stress levels regarding the children were very high. Parents did not acknowledge themselves or

external life stresses as part of the problem. The researchers suggest that the child may become a scapegoat, and be blamed for family difficulties. They therefore advocate evaluation of the parent/child relationship in treating the stress of family members.

Landolt et al (2002), in a similar study of burn survivors in Switzerland (n=105), also noted that parents reported fewer positive emotions in their children, although they indicated that they were no more troubled than healthy children.

Following a ten-year research review, Stoddard and Saxe (2001) claimed that following injury, the attachment behaviours developed in dysfunctional families may lead to difficulty in regulating the extent of self-blame and lack of trust in others. These families may also be unable to assist the child in the physical and psychological recovery from the injury.

The findings of these research studies strongly suggest that families should be provided with emotional and psychological support following discharge from hospital. In the British Child Accident Prevention Trust study, Heptinstall (1996) identified a significant level of post-traumatic stress among the parents of children who had had accidents. 20% reported feeling anxious or depressed for some time after the accident. Notably, none of the children or parents in the study group received emotional support after the accident; some felt that this would have been helpful if they had known how to access it. Study participants felt that their emotional state was ignored, and reported the wish to have someone outside the

family to discuss the accident with. The author also found that siblings often exhibited distress possibly as a result of a parent's absence in hospital.

2.8.2 Family adaptation theory

Also relevant to this subject is the theory of family adaptation after illness or injury. The ability of the family to adapt to the changes caused by injury or illness is also well explored in literature, although family adaptation theory specifically on burn injury appears to be limited. However, the themes identified in literature on family member adaptation can be seen as relevant to this study.

A number of authors have looked at the process of grief and recovery that parents seem to experience when coming to terms with the illness of their child. Barnett et al (2003) believe that the parents of, for example, special needs children, go through a process of grieving for the 'healthy' child they will never have. Most, according to the authors, recover and are able to go through a process of replacing their expectations with the reality of the child's prognosis. This process could be seen as similar to that experienced by parents coming to terms with the long-term medical treatment and scarring of a burn injured child.

The ability to adapt to the circumstances of the child's injury or illness is likely to have a significant effect on the parent's perception of the efficacy of the family unit. Svavarsdottir and Rayens (2005), in a study of parents of children with asthma,

found that parents who had high levels of individual resiliency viewed the family unit as resilient too.

Family resilience and its role in helping the family to adapt to illness is also an important element of the work of Tak and McCubbin (2002). The authors have identified the existence of social support as a factor for improved family resilience. In a secondary analysis of a longitudinal study involving 92 families with a child with a chronic illness, the authors discovered that those families who perceived high levels of social support were more likely to exhibit resilience. Those families exhibiting resilience were more likely to adapt well to the illness in a child, and would, therefore, experience a more positive view of parenting despite having to come to terms with the loss of the expected 'normal' child.

However, other research has sought to identify those families for which resilience is less likely to be high. Dellve et al (2006) in a study of the parents of children with rare diseases discovered that in particular single mothers or mothers with more than one disabled child were more likely to have high levels of perceived stress.

Barnett et al (2003) identify that high levels of stress and anxiety regarding the medical treatment of a child can have an adverse effect on parenting experience and marital satisfaction, as well as leading to difficulty in maintaining social networks. However, they report that psychosocial resources such as perceived control, social support and coping mechanisms seem to improve the parents' ability to parent the child effectively. Therefore, it could be suggested that families experiencing marital

difficulties and family isolation prior to the injury are less likely to be able to parent a burn-injured child effectively.

2.8.3. The effect of guilt on parental adjustment

Parents following childhood injury frequently discuss guilt; however it is rarely examined in depth. Some of the research studies already examined briefly remark on its importance but fail to expand. Fukinishi (1998) hypothesises that the post-traumatic stress and depressive symptoms experienced by parents are accelerated by guilt feelings largely because they feel they did not pay enough attention to their children. Kai (1996) also emphasised the influence of a sense of responsibility to act as competent parents and the fear of overwhelming guilt if they fail to do so.

Combes (1991) found that parents felt guilty whether they felt they could have prevented the accident or not, reinforcing her findings that parents felt they had prime responsibility for accident prevention. Considerable upset was felt by parents because of insensitive questioning, this may be as a result of an assumption on the part of health professionals that burn and scald injuries are caused mainly by the acts or omissions of parents (Gaffney 2000, Jeffery et al 2000).

The often-expressed view that accident prevention is mainly a matter of common sense may also contribute to guilt feelings. Haycock-Stuart (1999) describes the problem of when parents feel guilty and defensive at a lack of safety knowledge often considered by others to be a matter of common sense. If an injury occurs,

further guilt can be experienced if parents feel others are judging them as lacking in the common sense that might have prevented the injury.

Heptinstall (1996:13) described the intensity of parental guilt feelings, in a quotation from the mother of a twelve-month-old baby:

‘I would have liked people to understand the guilt I felt instead of just saying “Never mind, at least he is not badly hurt”’

The psychological effects of burn injury both for parents and the child suggest that support to cope with the distress is essential. However, Jenkins and Stanwick (1991) carried out a survey of all one hundred and forty-nine burn centres in North America and despite the accepted importance of psychological support following burn injury, a quarter of U.S. burn centres did not address this aspect in discharge support programmes.

Bearing in mind the significant psychological effects of the burn injury for the child and parents, it would be surprising if the experience did not have a dramatic effect on parenting experience. It is this effect that needs further exploration, as it seems likely that the feelings engendered by the experience will have an enduring effect on the family.

2.9 Conclusion

This review of the literature has demonstrated that the impact of burn injury on the child and the family is recognised by researchers and health professionals. The

evidence reveals that burn injury makes a significant contribution to the morbidity caused by unintentional childhood injury. It therefore has the potential to affect the life of the child and the family for a considerable period of time due to the need for long-term treatment and probable scarring. Available literature indicates that scarring from a burn injury may have a significant negative physical and psychosocial effect on the child especially as they move into their adolescent and adult years. The evidence suggests that family adjustment to the burn injury is vital, in order to ensure that the child recovers as fully as possible. It is also evident that routine support in hospital and post discharge is often lacking.

As a result of the complexity of the medical treatment, families affected by burn injury are likely to be involved with healthcare professionals over a considerable period of time. This factor makes the relationship between the family and the health professionals they encounter critical in family adjustment.

A number of authors have identified that family circumstances may contribute to burn injury risk; and it seems probable from the evidence available that those families most likely to be affected may be least able to cope with the trauma of the injury. This is coupled with the guilt feelings that parents are likely to experience as their child may be injured at a time when he or she may have been under direct parental supervision. The feelings of guilt and distress at having failed to keep their child safe are also likely to affect parental adjustment.

Bearing in mind that the consequences of burn injury on the family are enduring and significant, it seems likely that it will have a major effect on the views and feelings of mothers and fathers on how they parent their child over the initial recovery period, and in the future. These effects and the contribution of health professionals to parental adjustment will be examined in this thesis.

CHAPTER 3

METHODS

3.1 Introduction

In this chapter I discuss the method by which I conducted this research study. The background for the study and the development of the aims is described below and this is followed by an account of the process by which I decided on a qualitative method for data collection and analysis. The detail of the study method is described, including an account of recruitment of the study sample. The key aspects of the data collection are examined and an account given of the framework for analysis. The efforts made to ensure reliability and validity are discussed, as well as ethical considerations.

The research aim for this study arose directly from lessons learned whilst coordinating a local injury prevention project. From conversations with both parents and professionals, it became evident that although experiencing childhood injury was challenging for all families, for those experiencing burn injuries the effects on the family appeared to be longer lasting. Individuals who had experienced burn injury during childhood revealed that the injury had a profound effect on family relationships and professionals who routinely cared for injured children spoke of burn injury significantly affecting families for many months if not years.

It is evident that the trauma of serious burn injury is of major importance in the life of the child and their family, and is for many their first experience of acute paediatric care. The impression gained from informal conversations with both professionals

and parents is that the actions and attitudes of the healthcare workers dealing with the family has a significant effect on the emotions of the parents as they come to terms with the psychological trauma of seeing their child injured, as well as dealing with feelings of guilt and responsibility.

It therefore became evident that through further detailed exploration of these factors, the research element of the overall injury prevention programme could potentially gain valuable information on the psychological effects of injury on the family, as well as providing a useful insight into how health professionals can help and support parents as they come to terms with the effect of the injury on the family.

Once it had been established that research into these matters could provide significantly useful information, it became necessary to formulate a research aim that could encompass all of the required elements – the impact on the family and the changes that this engenders, as well as the contribution of healthcare professionals around the time of the injury.

3.2 Aim of the study

The aim of the study was therefore formulated:

To examine the impact of childhood burn injury on the family, and the parents' views of its effect on the long-term parent-child relationship; whilst gaining an understanding of their views, opinions and feelings about their healthcare experience after a serious burn injury to their child.

Once this research aim had been formulated, research questions were developed that would allow appropriate research data to be collected. In order to establish the questions a preliminary literature review of available research on the subject of childhood burn injury was undertaken. This helped to establish what concepts should be developed further in this context in order to meet the research aim. This was helpful in formulating initial research questions, and further refinement led to the following research questions for the study.

3.2.1. Research questions

- What were the feelings of the parents immediately after the injury occurred?
- How did the experiences of the family once admitted to hospital affect their feelings?
- Did the injury affect the parent's view of their relationship with their child?
- How did the injury affect their safety behaviours within the home?

Once this research aim and specific research questions had been identified, I needed to identify the most appropriate method for the research in order to most effectively gain insight into the identified aim. Below I outline the systematic and rigorous approach I developed to explore and develop deeper understanding of the subject.

It became evident that the issue to be studied, that of the impact of burn injury on the family required a research approach that would allow maximum opportunity for the participants to describe their own lived experience. The group to be studied would be describing their own experiences and reactions, which then would need to be studied and interpreted in the light of the experiences of others in the sample. The results of this would allow the formulation and development of theory based on the interpretation of human behaviour in natural settings and applied uniquely to individuals undergoing that experience, but transferable to others. The approach would therefore necessarily be highly subjective, suggesting that a qualitative approach would be likely to be the most appropriate in this case. Conversely, a quantitative research approach is designed to be objective, proposing that scientific truths and laws can be formulated and proven from observation and measurement carried out without bias. Such an approach would be unlikely to meet the study aim and answer the specific research questions. Therefore a qualitative approach was developed to answer the research questions.

3.3 Research method

3.3.1 The use of qualitative methods

Qualitative research, in its simplest form, is a means of understanding human experience. Greater depth in this understanding can be realised by taking into account the context of the experience, and interpreting the behaviour observed in interaction with wider society. In the case of this particular research study, the stated aim was to seek to understand the lived experience of parenting a burn injured child. A qualitative approach was therefore decided to be appropriate for the research. Using qualitative methods allows the researcher to take a holistic approach, looking not just at the injury to the child, but the experience of individuals in a family and also as a social unit. Topping (2006) describes qualitative research as sitting neatly within an interpretivist tradition, based on the assumption that making sense of the world is only possible by interpreting human behaviour in interaction with others. Moreover, data collected about an experience as it is lived reveals the reality of that experience, and the meaning given to it by the family. Oiler Boyd (1993) describes qualitative research as involving broad statements about human experiences and realities, studied through significant contact with humans in their own environments, and producing rich data allowing others to gain understanding of those experiences. Bergum (1991) emphasises this ability as a search for understanding, not separating the knowledge from the meaning of experience.

By supplying rich descriptions of human experience, qualitative research also has the ability to challenge the status quo by providing insights into difficult questions (Morse 1991a). Healthcare research has a tradition of exploring the views and perception of users as a means to inform change. Therefore, well conducted research studies into challenging issues can ensure that knowledge of the effect of illness on individuals and families, as well as the impact of professional involvement in care, can move forward knowledge and allow improved care.

It is also noticeable that there are few qualitative research studies about childhood injury, despite the need for a better understanding of why injuries occur, the environment in which they happen, and the contribution of behavioural factors. Roberts (1997) argues that well conducted qualitative research on childhood injury allows an explanation of why, rather than how often specific incidents occur, and also how parents perceive accident prevention strategies. Qualitative data can also inform policy by seeking evidence from those experiencing the problem at first hand. She endorses the use of case studies and critical incidents to look at why child injury occurs, but also supports a more detailed examination of injury prevention strategies to assess their unintended consequences, for example an increase in parental anxiety. These conclusions can, she argues, only be effectively drawn from effective and rigorous use of qualitative techniques such as interviewing or observational methods.

Roberts (1997) sees the use of qualitative methods as essential to understand how parents and children negotiate dangerous environments and prevent injury. It could be argued that equally careful use of a qualitative method can give valuable insight

into the effect that actual injury has on parents as they try to keep their children safe. Only by using qualitative methods to understand the impact of injury on the family can we hope to appreciate fully the effects on the parent's relationship with their child, and on their efforts to ensure that their child grows and develops safely in the future.

Having established that a qualitative research method is likely to be most effective to gain understanding of the lived experience of families affected by burn injury, it is necessary to decide which specific method is best suited to the aims of the study. The following part of the chapter is concerned with a justification for the choice of interpretive description as a method for the research described in this thesis.

3.3.2. The adoption of interpretive description as a research method

It has been suggested that nurse researchers, trying to ensure reliability and validity of their qualitative research have often sought to base their methods on the philosophical traditions of phenomenology, grounded theory or ethnography (Thorne et al 1997). However some nurse researchers, finding that these traditional methodologies do not always provide the means to advance the unique needs of nursing theory, have sought to develop these approaches. In some cases this has meant departing from the strict dictates of conventional qualitative research methods. Although these departures have been frowned upon as 'method slurring' or 'sloppy' research by some authors (Baker et al 1992), Thorne et al (1997) claim that nursing

researchers have been required to find a methodological alternative to traditional approaches in order to develop knowledge on health and illness experience.

Taking into account the need to find an alternative approach, Thorne et al (1997) have suggested a credible substitute for traditional methodologies, known as interpretive description. They argue that nursing researchers, taking account of the theoretical and philosophical traditions of the profession, have been able to build a distinct research logic aimed at formulating a set of ideas with potential for application, but always allowing reformulation in the light of new research. They suggest that interpretive description is an approach well suited to a research paradigm that accepts that the health and illness experience is by nature constructed and contextual, but which also allows for individual feelings and events to be accepted as truths. This approach is highly suitable for this study.

3.3.3. Key elements of interpretive description

Thorne et al (1997) assert that many nurse researchers, engaged in trying to understand the health and illness experience, are reluctant to use quantitative scientific methods. In the past, in an attempt to explore patient experience, they have aligned themselves with established methods in other disciplines such as philosophy, sociology and anthropology. However, as has already been argued earlier in this chapter, any departure by nurse researchers from the strict dictates of the research methodologies within these traditions has often risked criticism. Thorne et al (1997) therefore argue that, because traditional qualitative approaches do not always meet

the demands of nurse researchers, there is a need to develop methodological systems in the context of nursing science, rather than following rigidly the dictates of other disciplines. They take the position that nursing scholarship may have reached a point where it is timely to consider alternative, noncategorical qualitative approaches developed from an understanding of nursing's theoretical and philosophical fundamentals as valid and reliable methods of developing nursing knowledge. In their paper, the authors suggest interpretive description as such an alternative method.

In this introductory paper (Thorne et al 1997), the authors discuss a number of key elements essential in the adoption of interpretive description as a research method. These are summarised below:

- Critical analysis of existing knowledge on the subject to be researched should provide a foundational fore structure for the research, but will be challenged as the analysis proceeds.
- A varying sample allowing representation of views should be selected. The authors advocate purposeful selection of research participants whose accounts reveal elements shared by others. It should be possible to identify eccentricities in accounts, and explain why these occur. The principles guiding the sample selection, as well as the variables about which the researcher makes claims but also be made explicit in any report in order to make an interpretive description of the phenomenon convincing.
- Collateral data sources such as lay print or other media information as well as case reports and clinical papers can provide support to analytical findings.

These can provide a testing ground for developing insights, therefore adding strength to more conventional data sources.

- Inductive analysis should be used, without utilising premature or over complex coding systems as these can lead to superficial understanding at the expense of more meaningful analytic interpretation.
- The authors consider that questions such as ‘what is happening here’ or what am I learning about this’ will stimulate more coherent analytic frameworks than small coding or computer software (Thorne et al 1997:174). Analytic techniques that encourage repeated immersion in the data should be used. Interpretive description requires that researchers come to know each individual intimately, identifying and comparing common themes from within each case. These comparisons result in knowledge that can be then applied back to individual cases to allow deeper understanding.
- Attention to rigour in the reporting of the research process is critical. The authors consider that either field notes or a reflective diary is essential to allow tracing of analytical development, as well as recording the context of all data gathering.

Interpretive description has been seen to be extremely useful as a method for capturing individual accounts of lived experience, then allowing these accounts to be drawn together to formulate a theory about how patients or carers develop and adjust to these experiences. The method was used by Knoll and Johnson (2000) who interviewed eight spousal caregivers on their adjustment to caring for a cardiac surgery patient at home. The objectives of the study were to describe and interpret

the experience of becoming a caregiver, and identify the effect of this on family members. In their discussion, the authors compare their findings with those in other carer's literature, identifying the fact that in general this has concentrated on the experiences of those caring for elderly or chronically ill. In contrast, Knoll and Johnson (2000) use interpretive description to look at the life experience of people who have to unexpectedly care for individuals with acute health challenges. The use of this method allowed them to know and understand the individual experience of the participant, but also to recognise shared themes across all the caregiver's experiences. The authors also note the reality that the relationship between the carer and their spouse may be changed as a result of their experiences, and attempts to explain how the development of the care giving role helps to aid the patient's recovery and return to a normal life.

Davison and Simpson (2006) in a study of patients with end stage renal failure also used the interpretive description method to explore the needs of patients for support in end of life planning. They found that the patient's hopes for the future were highly individualised and shaped by personal values. The use of interpretive description allowed these very individual views to be analysed and compared with other experiences to identify truths about the concept of hope in terminal illness. The authors found that professionals were crucial in helping patients nearing the end of their life to maintain hope by being open and honest about treatment possibilities, and allowing patients to go through the process of reshaping their ideas and dreams for the future.

It is significant that both of these research studies use interpretive description as a method to explore and analyse the process of adaptation as the individuals discuss the changes in themselves as they have taken on different roles – either as carers after an acute health event, or as patients coming to an understanding that they are facing the end of life.

In contrast to other qualitative research methods, for example phenomenology, which requires that what is already known about a subject should be set aside, interpretive description should be undertaken in the context of existing knowledge about a subject (Thorne et al 1997). As already recounted earlier in this chapter, the choice of the research subject was informed by conversations with individuals and professionals who had some experience of burn injury, and were therefore able to offer context for the choice of subject. Further information about the importance of burn injury on the functioning of the family was then obtained from an extensive literature review from both academic and other sources prior to data collection. The findings were also constantly examined in respect to other relevant literature.

3.3.4 Reliability, validity and rigour within the research

A common theme for writers on qualitative research is the challenge of making sure that the method used is of sufficient rigour to ensure that the conclusions drawn can be seen as relevant and valuable. Having chosen interpretive description as a particularly relevant qualitative research method, the measures to be taken to ensure reliability, validity and rigour of the research study need further consideration.

Evaluation of the usefulness of an investigation implies application of standards of quality and value. However, the reliability and validity of qualitative studies can be seen as a problematic topic in the field of nursing research.

According to Koch and Harrington (1998:884), qualitative research is often attacked for lacking in 'scientific' rigour. They argue that quantitative evaluation criteria such as objectivity and generalisability are often used to assess qualitative work, inevitably leading to criticism that the results are 'anecdotal, impressionistic, and strongly subject to researcher bias'. Morse (1991a) sees the application of such criteria as a major threat to qualitative research, failing to lead to an increase in academic rigour. Keddy (1994:263) goes further, criticising qualitative researchers who have tried to fit the language of positivism onto inductive research in an attempt to satisfy criticism - 'a case of Cinderella's slipper'.

If there is acceptance that the aim of qualitative research is the interpretation of subjective experience (Hill Bailey 1997), then developments on the understanding of the origins of social meaning have led to an understanding that qualitative findings are distinct from the results of positivist enquiry. The findings, therefore, as subjective interactive constructions should no longer require verification from a quantitative perspective. In consequence, as the tradition of qualitative research enquiry in nursing has grown, it has become desirable to find an alternative means of ensuring validity.

Beck (1993) has described this process of the evaluation of the credibility, fittingness and auditability of qualitative research, reflecting on the fact that in the past nurse researchers have often tried to use the same measures of reliability and validity with qualitative work as quantitative methods, and found them to be inappropriate.

Instead, she describes other evaluation measures, in particular drawing on the work of Lincoln and Guba (1985) who describe four criteria for the validity of qualitative research; truth-value, applicability, consistency and neutrality. Appleton (1995) has also given an account of how the measures were used in a study on the health visitor role in working with vulnerable families in relation to child protection. Since the stated aim of the research reported in this thesis was that the results should accurately reflect the opinions and feelings of the participants, as well as be applicable in other settings, it can be seen that applying these measures to this research will help to address the issue of rigour in qualitative research.

- *Truth-value* refers to vibrancy and authenticity in the description of the phenomenon resulting in confidence in the 'truth' revealed. This is addressed by the use of direct quotations from tape-recorded and transcribed interview data. Careful reading of the text, listening to the tape recorded data and making comparisons with the data from other interviews also ensured that the descriptions of each theme remains authentic. The use and meaning of each quotation was also discussed with two university supervisors, who had read the whole interview transcript so were familiar with its content.

- *Applicability* is possible when data can fit into another context than that in which it was engendered. Analysis of the findings presented in subsequent chapters indicates that a number of the themes identified in the research can also be seen as applicable to other settings and contexts, in particular those involving parenting within healthcare settings, as well as adjusting to illness within a child.
- *Consistency* implies the findings are likely to be repeated if the inquiry were to be replicated in a similar context. Although it is recognised that burn injury has a significant effect on family functioning, the direct effect of a burn on parenting has been rarely studied. However, the links that are drawn to other already established work during the analysis seems to imply that further work on this subject would yield similar, complementary results.
- *Neutrality* refers to the decisions made by the researcher at every stage of the research process to avoid introducing bias. Unlike phenomenology, the interpretive description research method does not require that what is already known about a subject should be set aside. However, it is important that new conclusions drawn from the analysis are not affected by the findings of other researchers, or by a wish for certain findings to be revealed. Making explicit the inductive process used to develop the analytic themes approaches this.

It is necessary for the researcher to take into account the possibility of error occurring due to participants responding with socially desirable answers that they

believe the researcher wants to hear, rather than the truth. Using open questions with no 'correct' or desirable answer, as well as the use of multiple approaches to questioning during the interviews addressed this.

It is also important to recognise that the opinions and feelings of the participants are not objective or based on facts, nor can they accurately present the perceptions of others, for example the child (Holloway and Fulbrook 2001). Therefore, at all times it was necessary to take into account that the participants were discussing their own unique lived experience. However, by employing the interpretive research approach it becomes clear that the lived experience of each parent is individually constructed, but can be interpreted in the light of the experiences of others.

3.4. Research design

3.4.1 Setting

The setting for the research was a mixed urban and rural area in the central belt of Scotland. At the time of writing, the population is approximately 160,000 but the area has a higher than average proportion of inhabitants under the age of forty. The population is projected to grow by twenty-one percent in the next ten years, due to the area's central location for access to larger cities. A large part of this growth is expected to be due to an influx of young families attracted to the area by economic growth and relatively low property prices. There are consequently a number of parents living away from their extended families. Recent large-scale job losses

locally have increased economic uncertainties for many, and there are a high number of families with both parents working.

In contrast to the relatively high standard of living evident in the newer settlements, a significant part of the population lives in and around the older towns and villages. Due to the loss of traditional industries in these areas and consequent economic decline, there are a significant number of families living in relative deprivation. These families are recognised as being at risk of social and economic exclusion.

At the time of data collection, community health care was provided by a unique integrated trust incorporating twenty-four GP practices and community healthcare staff. Secondary paediatric care was and still is provided by an acute hospital treating inpatients, ambulatory paediatrics, and minor paediatric burns. More severe burns requiring resuscitation, intensive care or surgery are transferred to the specialist children's hospital in the nearest large city. This provides regional paediatric burn services on a dedicated ward, as well as through outpatient facilities.

3.4.2 Sample

The principle of sample selection in all research is critical to ensure that the end result is of sufficient quality to contribute significantly to the knowledge of the subject studied. In quantitative research, strict principles on the selection and size of samples have been developed, and detailed descriptions of how these rules should be applied are available in many standard texts on nursing research.

The principle of sample selection in qualitative research has been less frequently discussed in the qualitative literature (Morse 1991b). This has resulted in much confusion among qualitative researchers, many of whom have attempted to use sampling techniques more appropriate to quantitative research, for example using some form of randomisation. Morse (1991b) argues that sticking too rigidly to an inappropriate method of sample selection for qualitative research ends up violating the principles of both quantitative and qualitative research – the resulting sample will fail to be either sufficiently large or sufficiently informed to meet the needs of the study.

The basis of qualitative research is that individuals are best placed to describe their own experiences in their own words, and through this the researcher can uncover the meaning participants give to their experiences and the way they interpret them (Holloway and Wheeler 1996). Understanding this basic principle of qualitative research implies, therefore, that the researcher can only gain the necessary information from those who have experienced the phenomenon to be studied. The challenge among qualitative researchers is to find participants that are best able to provide adequate information on the subject to be studied, as well as being sufficiently articulate, reflective and willing to share experiences that may be distressing when recalled. These are of necessity the basic criteria for selection – in this sense all the samples for qualitative research are purposive, that is, the criteria are decided upon and the sample selected accordingly.

3.4.2.1 Inclusion/exclusion criteria

For this research project, the sample was selected from parents of children under five. The age criteria was decided on for three reasons: the first because burn injury is of particular significance in children under five due to the numbers involved nationally, as well as the usually extensive physical impact on the child (DTI 1999). Secondly, the pre-school years are also the time when the child is likely to be located in the home, largely under the supervision of adults. The third reason for the criteria was that the research study was undertaken as part of a project aimed at reducing injury in children under five.

It is evident that burn injury covers a wide spectrum, from a relatively minor scald on a finger to extensive life threatening burns covering a large area of the body. Morse (1991a) advocates that participants should have a substantial experience of the phenomenon; therefore it was necessary to ensure that the burn injuries experienced by the families included in the research study should have had significant impact on their lives. Arguably, it is unlikely that a minor burn would have more than a fleeting effect on the family, although it was probable that there would be parental awareness of a 'near miss' (Roberts 1996). With this in mind it was essential that criteria for inclusion were formulated that would ensure that participants had considerable memory of the events. To make certain of this, it was decided that only the parents of children who had experienced burns of sufficient severity to require transfer from the local district general hospital to the specialist paediatric burns unit in the nearest large city would be recruited for the research study.

It was also decided to specifically exclude proven cases of non-accidental burn injury from the sample due to the sensitivity and complexity of the issues surrounding these families. This decision was not taken due to lack of potential numbers, as one author has estimated 3-10% of paediatric burns are due to non-accidental injury (Hettiaratchy and Dziwulski 2004). However, as many of these cases require protracted and distressing child protection enquiries it was felt it would be inappropriate to include them in this study. It was also seen as necessary to exclude families where the burn injured child had died. It was considered insensitive and distressing to include these families in this particular project.

Due to the lack of interpreter support for the study, only parents who could speak fluent English were recruited.

Participants who met the inclusion criteria were recruited to the study at least six months after the burn injury, but not more than three years. The minimum length of time stipulated was to allow initial shock and distress from the injury to reduce. Allowing a gap of six months between the injury and the time of interview was also a requirement of the ethics committee granting ethical approval for the study. It was also important to ensure that the interview did not take place more than three years after the injury had occurred. In practice, the majority of the interviews took place around six months to a year since the injury had occurred. However, ensuring the interview took place less than three years after the accident ensured that the details sought were likely still to be recalled. It was noticeable in all the accounts that the parents were able to answer the interviewer's questions readily and without

noticeable effort in remembering what had happened. The level of detail provided by all the participants indicated that the memories of the events recalled were still extremely clear in their minds.

The sample specifically excluded participants from the researcher's own health visiting practice. At the time of recruitment, it was anticipated that the participants would have had significant involvement from community nursing staff, and the exclusion of participants from the researcher's own health visiting practice area was to ensure that families were able to give honest and unbiased accounts of their experience of health visitor intervention before and after the injury.

Therefore, a study sample of nine families was recruited with twelve parents and one grandparent interviewed during nine interviews. Appendix 1 contains a table detailing the participants for each interview.

3.4.3 Arranging access

The researcher's role in coordinating a local injury prevention project helped to ensure that local healthcare professionals had become aware both of the extent of injury to children under five in the area, as well as the impact of burn injury on families. The research element of the project had also been given management approval, which permitted local health visitors to give work time to the recruitment of participants to the research.

Health visitors from the whole of the study area were given an information letter on the project, and asked to identify children on their caseload who had experienced moderate to severe accidental burn injury while less than five years of age. The criteria for inclusion were provided in the letter to ensure that families who did not meet the criteria would not be approached. The health visitor was asked to contact the family to ask if they would be willing to participate in the research.

If the parent indicated interest in participating in the research, their name, address and contact details were passed to the researcher either by telephone or on the pro-forma reply slip included with the health visitor information letter. The researcher then sent a letter and information sheet to the families identified, indicating that they would be contacted by phone after at least seven days to ask if they agreed to take part in the research. If telephone contact details were not provided, a suggested date for a short visit was given to discuss the research.

The researcher's name and contact details were provided, as well as the name and contact details of a local health visitor researcher. This individual was identified to the potential participant as an independent person who could answer questions regarding the research. No parents contacted the independent person at any time during the conduct of the research.

During the initial telephone contact, the researcher reiterated the details of the study to ensure that the parent had been able to understand the information sheet about the project, answered any further questions and arranged a mutually convenient time for the interview to take place. The parent was informed that the interview should not

take more than an hour, but that plenty of time should be allowed to ensure they were as relaxed as possible during the interview. Permission was also sought to allow a letter to be sent to the family general practitioner requesting contact with the researcher if interviewing the parent was, in the opinion of the doctor, not in their patient's best interest. No general practitioner responded to this request with regard to any of the families recruited.

As the study progressed, other health professionals working in the area became aware of the project, and informed the researcher of eligible families known to them. In these cases, exactly the same procedure was used to recruit participants. In addition, the Scottish Burned Children's Club discussed possible inclusion with their members living in the area, and was to pass on family details to the researcher if permission was granted. However, no suitable participants were identified through this route.

Informed consent was sought at the time of the first visit, after the study was verbally explained. The participants were asked to sign two copies of the consent form. The interviewer signed both forms, one was left with the participant and the other filed securely in a locked filing cabinet. The researcher ensured that any questions participants had were answered, and also made contact details available should the participant have further concerns about the research they wanted to discuss. It was emphasised with each participant that they could withdraw their consent at any time in the research process.

Copies of the parent letter, information sheet, consent form, health visitor and general practitioner letter have been included in appendices 2, 3, 4, 5 and 6.

3.4.4 Data collection

Data collection was carried out between 2002 and 2005. Nine families participated in the study, and a total of thirteen people were interviewed. Each participant was interviewed once by the researcher; for some this interview had both the mother and the father present, in others only the mother was interviewed. In the case of one family, the injured child's grandmother was also present and joined in with the interview. The researcher had not specified before the time of the interview who should be present, this choice was left entirely to the participants. A summary table of those interviewed can be found in Appendix 1 of this thesis. Each interview lasted a minimum of one hour, with some extending to longer periods of up to two hours.

Participants were interviewed in their own home, at a time convenient to them. The use of the home as an interview venue ensured the participant incurred no travel costs, and being in a familiar environment increased the participant's comfort. There was no funding available for childcare, so in most cases interviews were arranged when the child and siblings would be at school, playgroup or nursery. Some children were present at the time of interview; due to the participant's own choice.

In order to allow complete recall of the interview, an audio tape recording was made. Each participant was asked for permission for the recording to take place. The

interviews were then transcribed and the tape and transcript were stored in a locked cabinet.

The researcher also wrote a reflective diary as soon as possible after the interview to recall impressions of the participants, and to capture important data that might have emerged at the beginning or end of the tape-recorded interview.

Wimpenny and Gass (2000) among others advocate the use of interviews for qualitative investigation as it allows for open exploration of the experience of the participant. It was important that the data collection allowed the uncovering of all the views and opinions of the participants in order to allow interpretation, and although previous reading on the subject informed the investigator's initial approach, early interviews were unstructured.

However, May (1991) describes the challenge of maintaining a balance between allowing sufficient flexibility to extract the stories of the participants, but enabling enough information to be gathered to allow comparison between subjects. Consistency was attempted by asking the same questions of as many different participants as possible. An interview schedule can be found in Appendix 7 of this thesis.

A semi-structured interviewing technique was utilised. Open questions were used in order to collect information on all areas of interest and subsequent questions were asked using the same or similar language to that used by the informant. Participants

were often asked to clarify statements by giving more information in order to ensure understanding. With reference to collecting data on the effects of the injury on the family, the researcher asked very few questions, allowing the parents to speak as specifically as possible about their experiences, thus allowing them to clarify what they meant themselves, often later in the conversation.

Specific data was obtained by asking parents for information on the family situation around the time of the accident, and demographic details on the family. Topics discussed in depth included the parent's perception and their opinions on the staff encountered during hospitalisation and subsequent to this, and their perception of the roles that the staff filled. Discussion also took place on the safety measures taken by the family before the accident, and the change in safety behaviours exhibited by the parents and extended family as a result of the injury.

However, as analysis identified common themes, a structure became more evident. The interview schedule was therefore followed, but as preliminary analysis of earlier interviews had revealed subjects of interest, further questions were asked to develop this theme across later interviews. Large sections of the interviews were concerned with the feelings experienced by the parents at the time of the accident, and subsequently.

3.4.5 Data management

The researcher transcribed each interview. This was felt to be important, as a number of the participants had strong local accents, making the tape recording difficult to decipher without a strong sense of exactly what was being discussed at any point in the recording. Following transcription, the interview was read closely and the tape listened to again to gain a sense of the whole, then a line by line analysis of the data was undertaken where the researcher constantly questioned the data in order to identify topics and ideas. These were then analysed using the following method.

3.4.6 Data Analysis

As has already been seen in the discussion of the research method used, Thorne et al (1997) advocate a method of analysis that involves repeated immersion in the data. Therefore, following transcription of each interview, the transcript was repeatedly read and reread and the audio recording listened to simultaneously. Significant comments made by the participants were identified by underlining the transcript. A time line was then formulated, with common landmarks such as initial admission to hospital, surgery and discharge marked. The parent's discussions on their experiences at various times in their child's injury journey were brought together for comparison by a simple coding of interview and page number. Quotations from each interview were then grouped together using a word processor package cut and paste

method. The use of analytical software was considered, but packages available at the time were not considered to be appropriate to the approach.

This initial method of categorisation was utilised to avoid what Thorne et al (1997:174) describe as premature and complex coding, leading to overwhelming detail that inhibits the inductive process that is so integral to the qualitative research tradition.

Once this first step had been completed, quotations from each section of the timeline were examined in detail, with continual questioning of the data as to what exactly the participants were saying, and what meaning could be inductively derived from each quotation. The original transcript was frequently referred to, to ensure that this meaning was not taken out of context, and also to promote intimate knowledge of the data sources (Thorne et al 1997).

Following this process, similar ideas from each interview were brought together under a provisional category that was inductively developed. For example, 'Meeting the needs of the child, the parent and the family' was derived from parents expressing the need to have support and help not only for the child following the injury, but also for themselves. These provisional categories were then grouped into themes, and the whole examined to identify the meaning of what the participants said regarding their own experiences, and how this related to the other participants interviewed. Constant comparisons between the interviews and continued use of the

timeline during this stage resulted in the identification of a three stage process of parental adaptation with a clear temporal element.

During this process, it was possible to identify that a number of participants had similar experiences that could be compared to formulate theory; there were also participants who discussed differing experiences. This demanded examination of why these differences might have occurred, and this is reported in the analysis chapters.

It was also important to capture the themes identified when the parents discussed their healthcare experiences. Again, groupings were made of similar ideas expressed during the interviews, and these were grouped and categorised in the same way. Links could then be drawn between the adaptation process themes, and those identified by parents within their experience of healthcare. These linkages allowed recommendations about how healthcare professionals could support parents in their parental adaptation to the changes in family life engendered by their child's burn injury.

The results for this process are presented in this thesis. In order to reflect the strong views of the parents interviewed, direct quotations from the data are used to demonstrate how the views and opinions of parents have informed my analysis. Each quotation from the text is coded with the interviewee identification number, page and line number. In all cases, the words of the interviewer/researcher are clearly identified.

To reflect the personal nature of the words used by interviewees, I felt it was important to use names rather than initials when quoting from the data. However, to protect the confidentiality of the participants these names have been changed.

In considering interpretive description as a credible alternative to traditional descriptive research methods, such as phenomenology, Thorne et al (1997:173) claim that the method should be firmly grounded within the existing knowledge of a subject. Allowing the findings of such research to be thoughtfully linked to the previous work of others allows the formation of a 'foundational forestructure' for the new inquiry. They suggest that an analytic framework for the new data can be formulated by critical analysis of existing knowledge. This framework, developed by literature review, represented a starting point for the enquiry, and was therefore inevitably to be challenged and added to as the enquiry continued. In addition to using the examples from the interviews to illustrate the process of adaptation, relevant literature will be used to establish what is already known on the interpretation of each theme.

3.4.7 Ethical considerations

Munhall (1988) raises three important issues in ethical considerations for qualitative research: advocacy (the therapeutic imperative of nursing) must take precedence over advancing knowledge (the research imperative). If conflict occurs, participants must not be treated simply as a means to an end, but as individuals. Informed consent is

not a static concept; therefore consent must be seen as a continuum over the life of the project.

With these issues in mind it was intended to ensure, as far as possible, that involvement did not contribute to the trauma of the original event for the family. May (1991) suggests that as interviewing is a process of human interaction, therefore all the potential dangers of interaction are likely to occur for example, anger, misunderstanding and conflict. It was vital therefore that the researcher approached the encounter with the family with as much sensitivity as possible. It was emphasised that the participants were free not to answer questions or discuss issues that they did not wish to, and that they were free to renegotiate or withdraw consent at any time until the project was completed.

The participants were all National Health patients; therefore ethical permission was sought from and granted by both local and regional Research Ethics Committees in September 2001. Copies of the relevant letters are included in Appendix 8 of this thesis.

Confidentiality was emphasised at a number of stages before data collection, and it is not possible to identify individual participants from the findings. The participants were informed that although their health visitor and GP were aware of their inclusion, information was not passed onto any professional without their express permission.

If distress was evident during or immediately following the interview, the researcher asked the family's permission to refer them to their health visitor for ongoing help and support. In every case following the interview and with permission, the family's health visitor was asked to contact them to ensure that reliving the experience did not cause undue suffering.

It is also important to reflect on the reason for the investigation. Although one of the stated objectives of the research was the improvement of healthcare of families experiencing burn injury in the future, this concept may have limited meaning to parents still coping with the reality of the guilt and distress caused by the original incident. The value of talking to an empathetic and interested observer should not be underestimated, however the fact that the researcher will gain more benefit than the participant was made explicit both in the information sheet and during conversations immediately prior to and following each interview. It was also emphasised that the family was under no obligation to take part in the research, and deciding against participation would not affect the care of their child either then or in the future.

3.4.8. Limitations of this study

It is important to recognise that this study had a number of limitations. At the beginning of the research study, it became evident that the issue to be studied, that of the impact of burn injury on the family required a qualitative research approach. The study design formulated involved semi-structured interviewing of participants who had experienced a significant burn injury in their child.

This approach meant that the study sample was relatively small, containing nine families. However, each interview resulted in extremely detailed and rich data, allowing interpretation of the lived experience of thirteen individuals. Each of these individuals narrated their own stories, which allowed analysis and interpretation in the light of the experiences of others in the sample.

It is possible that a considerably larger sample would reveal a greater breadth of experience; however, the nature of interpretive description as a research method means that interpretation of the experience of any participant can be applied uniquely to that individual, but results in the development of a theory transferable to others. This, therefore, means that the lived experience of one individual allows a theory to be developed, which can then be tested and refined as others tell their stories.

This study was conducted in the United Kingdom, which has a healthcare system that is free at the point of delivery. This meant that parents did not discuss the burden of paying for their child's care, which might have affected their views and opinions on healthcare services. A similar study conducted in a setting where healthcare is paid for at the point of delivery might have different results.

All the study participants spoke English as a first language, as due to lack of interpreter support this was a criterion for inclusion in the study sample. It is possible that a parent of a different ethnic origin or speaking a different language would express very different views and opinions on matters such as communication.

3.5 Conclusion

This methodological chapter has set out to describe in detail the conduct of the research study. The background to the research aim and questions has been discussed, and the choice of interpretive description as a research method has been justified.

The research design has been described, and the analytic framework discussed. There has also been a discussion on the measures to address reliability and validity of the research. The final part of the chapter is concerned with the ethical issues surrounding the research, and how these were dealt with.

The next four chapters contain the analysis of the data, and an interpretation of the narrative accounts of the lived experience of the participants.

CHAPTER 4

‘WE WOULDN’T LET HIM AWAY’ HOLDING - THE FIRST STAGE OF PARENTAL ADAPTATION.

4.1 Introduction

All of the parents described in detail their experiences during the hospital treatment of their child, and it became apparent that seeing their child undergoing care was deeply challenging for them. It also became clear that examining the effect of burn injury on the family revealed a process of adaption to the injury. During the interviews, parents described at length their actions and reactions following the injury, discussing their thoughts and feelings immediately after the injury and as their child recovered. Participants outlined a transformation in their behaviour with the child, adjustments in their ideas of parenting and long term changes in their views of child safety.

The title of this chapter ‘We wouldn’t let him away’ (Father 1, page 21, line 3) encapsulates the reactions of many of the parents interviewed as they described how they had sought to protect their child from the dangers of the environment, as well as trying to ensure the child felt safe and secure by holding them safe within the family unit. Although one would expect the injury to have an immediate effect on the family, analysis of the data revealed long term consequences on the relationships within the family, and in particular between the parents and the injured child.

4.2 Parental adaptation

Rizzone et al (1994) interviewed twenty-five parents of burned adolescents in the United States and described changes in parental behaviour following injury. For example, some mothers reported constant concern about where their child was, as well as sleeplessness and becoming overly protective of the child. Significantly, more than half the parents questioned indicated that they were still experiencing severe post-traumatic stress symptoms a number of years after the injury had occurred. These included flashbacks, hyper vigilance and recurrent recollections of the event. This suggests that the experience of burn injury in a child has a very long-term effect on the psychological health of the parent, and therefore inevitably the family.

Long term psychological distress in the relationship between parent and injured child was also a finding reported by Rose et al (2005). The authors collected data from the parents of 208 children attending a large specialist burn centre in Texas. The participants were asked to complete the Parenting Stress Index, which measures stress in both the parent/child relationship, and also the stress experienced by the parent in their normal life. The results indicated the participants reported intense distress in their relationship with the child, perceiving them to be poor to adapt, unrewarding to parent and moody.

These studies have provided interesting and useful information on how burn injury affects parents and families, but there is little detailed recent literature on how

families adapt to these psychological changes. One set of authors who have formulated a coherent theory of adaptation is Watkins et al (1996). As a response to their realisation that the quality of family support is the most important issue affecting the adjustment of a burn injured patient, they propose a model of adaptation for family members.

The model developed by the authors has four phases, and is therefore identified as a process that the family members go through in order to adjust to the reality of coping with the burn injury of a loved one. According to the authors, there are four phases, described as crisis, control, commitment and consequences. These were presented in the literature review on page 34.

Watkins' et al (1996) theory of post-burn adaptation has relevance to the study findings described in this thesis; however there are certain areas in which important differences can be identified. It is crucial to note that Watkins et al (1996) based their model on the experiences of a range of burn injury patients and families. The three case studies that they use to illustrate their theory include the mother of one child of 7 and two adult spouses. In discussion, they are careful to mention that they base their work on the experience of adult family members. This is because, unlike children and dependant family adult members, in the latter stages of adaptation 'autonomous, adult family members' have the option of ending or replacing the relationship with the burn survivor. Watkins et al (1996:80) suggest that without having this choice, the family member is unable to renegotiate the relationship.

However, it is open to discussion under what circumstances a parent could renegotiate a relationship with a child.

This question demands the development of further knowledge of how individuals with a burn injured child adapt as parents. My analysis of the data seems to indicate that the individuals interviewed do undergo a very specific process of adaptation, demonstrating different concerns and behaviour at each stage of the process.

4.3 Introducing the three stage parental adaptation model

Intrinsic to all of the three stages of the adaptation model identified through this thesis was the realisation that a crucial parenting role is in protecting the child. Parents who have experienced seeing their child seriously injured feel an even stronger imperative to protect the child from the world (Roberts et al 1995). Therefore it is unsurprising that through all of the three phases of parental adaptation a common theme of protecting the child can be seen, with participants expressing a need to protect their child from the environment, from threat to the parent/child dyad, and from the prejudices of society.

There are therefore three phases of parental adaptation to burn injury in pre-school children that I have identified from the interview data. Each of the themes will be summarised briefly in this chapter, and examined in detail in the second part of this chapter, and the two following.

I have named the first phase of parental adaptation 'Holding'. This is demonstrated by the parent keeping the child physically close to them, but also describes the parent demonstrating concern that they should be identified by professionals as pre-eminent in the child's life.

The second stage of adaptation can be described as 'Guarding'. In this phase, the parent watches over the child to prevent further injury, and also develops strategies to regain confidence in their ability to keep the child safe under the potentially critical gaze of professionals.

In the third stage, 'Defending', the parents can be seen as seeking to protect the family and themselves from the shame of the injury, and also the child from teasing and embarrassment due to their physical appearance. In addition, they seek to prevent the child from being a victim in later life, therefore suffering long-term adverse consequences from the injury.

Each of these stages requires the parents to seek specific responses from health professionals. Examination of interview data reveals that at each stage parents were aware of the effect that their behaviour had on the professionals involved in the care of their child, and they were very clear how they felt they should be supported at every stage. This factor is also discussed in Chapter 8.

4.4 Holding: the first stage of the parental adaptation model

The parents interviewed for this study had experienced a severe injury to their child, therefore it might be expected that this impulse to hold the child physically close would be strong. With this in mind it is unsurprising that keeping the child close was to be a recurring theme in the interviews. However, the instinct to hold and be in close proximity to the child was more than simply an instinctive need to comfort and help the child. This was an important element that analysis revealed to be a natural impulse to hold the child to comfort them and to protect them from both the alien world of the hospital and the dangers of the environment. I have labelled this sub-theme ‘instinctive holding’.

The second and more complex element that could be identified from the data was the parent’s desire to be seen to hold the child close, to be physically identified as the most important human being in that child’s life, and thereby regain some of the power lost by having their ability to parent open to professional scrutiny. This sub-theme is described as ‘intentional holding’.

In the remainder of this chapter I will discuss in detail the two sub-themes of instinctive and intentional holding as revealed through analysis of the data, and also consider how these findings can be related to the relevant literature on the subject, in particular psychological theories on parenting.

4.5 Instinctive holding

In the interviews, parents describe at length their overwhelming desire to hold the child close. How this is enacted is dependant on the circumstances they are in; when possible they seek to physically surround the child with their arms; when forced to separate from the child in order for treatment to take place, they attempt to ensure that their presence in the room is allowed by health professionals. The descriptions given by the parents of their feelings at this time emphasise the importance of the bond between parent and child when the child's security with the parent seems to be compromised by separation.

The instinct to hold and comfort an injured and distressed child was an element described by all the parents interviewed. For some of the parents interviewed, this need to hold the child was immediate, and was often connected with the attempt to give first aid. Others describe their need to keep the child physically close throughout the time of their admission to hospital. The initial holding of the child to provide first aid was described in a variety of ways in the different interviews. For example, Mother 1 had fairly extensive first aid training as part of her job, and describes her actions very clearly:

Mother 1 '.....and I just thought "Right". I just grabbed him.....and I just dumped Lewis right in the sink., and I was sloshing cos its like a mixer tap, I was sloshing the water.' Page 5 line 40

Other parents were unsure what they should do initially, and although holding the child in an attempt to comfort them, their lack of first aid knowledge meant that panic reduced their ability to reassure the child. In particular, Mother 5, who was

young and inexperienced, described what she clearly felt were futile attempts to help her child:

Mother 5 'I was really scared and just running about, which made her cry. I ran through to the bathroom with her, trying to take the clothes off her, but I was that hysterical I couldn't do it.' Page 2 line 44

For this mother, the panic she felt when her daughter pulled a jug of boiling water over herself was still evident during the interview, even though the injury had occurred more than a year previously. In particular, she appears to attach blame to herself for distressing the child further.

Another mother used the word 'panic' during her description of how the injury occurred to her two-year-old child when he poured a cup of hot tea over himself:

Mother 7 'I panicked. Um, I sat him on the couch and straight away took his clothes off. Luckily his dad came through the door, so he started putting water on him.' Page 2 line 27

For this mother, her initial reaction was to remove the child's clothes, although she clearly felt that the child's father had more knowledge of burn first aid. Her instinct to help the child following the injury however was very strong.

Once the child had been taken to hospital, the responsibility for treatment of the injury was transferred away from the parent to the health professional. However, the instinct to hold and comfort the child in the alien environment of the hospital was for many parents almost overwhelming.

The response to this in some of the accounts was to bodily hold the child, almost clinging to the child to physically resist removal from the protective circle of the mother's arms:

Mother 1 'I kept saying to them "See if you take him away from me, he'll start screaming, don't take him away from me cos I know that would make him worse."' Page 7 line 6

Her expressed feelings suggest that she desperately wanted to protect the child by holding him close. Her reaction could appear to be paradoxical; she knew that the child would need treatment, but felt instinctively that by taking him away from her, he would become distressed.

Another mother expressed real fear that she might be prevented from holding and being close to her injured child. Doubts had been raised by medical staff about the exact cause of the injury and thorough child protection investigations were carried out, but intentional injury was dismissed. The mother felt that she had been unable to account properly for the injury in the eyes of some health professionals. Therefore the attitude of medical staff led her to be unsure whether she would be able to rejoin her child on the ward when she left the hospital, a prospect she viewed with dread and a very real fear that the child would be removed from her care and protection:

Mother 2 'That one night, we had to leave him in the hospital and I was away for 3 hours and that was torture cos I thought I was going to come here, get clothes and that and they wouldn't let me back in, keep me off him.' Page 9 line 47

The fear of being prevented from physically holding the child is emphasised by the expression 'keep him off me', where the mother again mentions physical proximity to emphasise the closeness of the relationship between parent and son. In this extract

from the interview, she is expressing an awareness of outside forces threatening to separate the mother/child dyad. Later in the interview, this participant expressed a deep distrust of the motives of some of the health professional staff, so this extract demonstrates a view that the ‘outside forces’ had what she felt to be a malign wish to keep her away from her child.

This feeling of outside forces removing the child is encountered in other accounts. One mother, who had found staying in hospital to be very stressful, describes occasions when she felt compelled to allow the staff to remove her child from her care in order to carry out treatment. She appears to feel that no explanation for the removal was given; that the child was just taken from her:

Mother 8 ‘They said ‘Oh, we’ll just take him’ The first couple of times I just let them because I didn’t know what they were going to do, but I just had to let them do what they were going to do.’ Page 5 line 5

The helplessness that the mother felt is very evident in this excerpt. Her words, in particular the repetition of the word ‘just’ strongly suggest that she felt impelled to allow the control of her child to be given to others, despite the fact that inadequate explanation was provided.

In contrast to this view, some parents apparently felt they had more control over where the child was taken. In this extract from the interview with Mother 1 she describes the intensity of the feeling that the family shouldn’t be physically separated whilst in the hospital. As their only child experienced the injury, both parents felt free to stay in the hospital, and were clearly able to ensure that they maintained physical proximity to their child:

Mother 1 'He was in beside us (laughs) because we wouldn't let him away. Well, we stayed with him for the full month, we lived in the house that they have there, it was outside the building, and to begin with I wouldn't go out, I kept saying no, no, we've both got to be there.' Page 21 line 3

Here, Mother 1 is expressing the overwhelming feeling she experienced that she had to keep her child with her, not letting anyone come between them. In addition, however, she is suggesting a stronger sense of control and choice as to where the family were on a daily basis. Her statement 'We wouldn't let him away' implies that the parents were not only able to argue their case to be with the child constantly, but also ensure that wherever the child went, they accompanied him.

4.5.1 Being there for the child

These accounts suggest that while some parents felt a strong desire to be physically near the child, others describe these feelings as belonging more to the child than themselves, providing examples of when the child demanded their presence in order to feel safe:

Mother 8 'He was quite, he had to go to sleep before I went, he's one of these children who likes you there.'

Interviewer 'He likes to have you there, did you have to cuddle him to sleep?'

Mother 8 'Sometimes he would fall asleep and then wake up and not realise where I was.' Page 5 line 29

This is typical attachment behaviour according to the work of Bowlby (1980), where he describes these actions as evident when the child is particularly aroused due to a frightening stressful situation. In these circumstances, the child may demand to touch or even cling to the parent. Other parents describe their child continuing to

demand parental proximity, especially in relation to sleep. In the following interview extract, Mother 7 tells how her son demands that she stays next to him in order for him to be willing to sleep:

Mother 7 'It took months to get him back sleeping. Once he used to go down awake and we just used to say good night to him. But even now he won't go down awake, he has to be sleeping, so it's going to take a long time to get him back sleeping. He's started to go down a bit better, but I have to lie on the bed with him (laughs).' Page 7 line 48

Other parents also mention that the instinct to hold and be close to the child was a result of the child exhibiting proximity-seeking behaviour. In interview 1, the mother describes her child as constantly looking for the presence of his parents to make up the family unit where he feels safe and comfortable.

Mother 1 'He's got to have the unit, like it's my mum and dad and me, we're family.' Page 28 line 3

This is reiterated later in the interview, when she describes his behaviour at a children's party when his father appeared to leave him to take another child to the bathroom. It is evident from the narrative that other familiar adults surrounded the child, yet he had developed a fear of abandonment. The words ascribed to the child seem unusually adult, suggesting that the words are the mother's own used to vividly describe the child's distress at appearing to be left alone:

Mother 1 ' "Oh, my god, he's left me'" That's what he kept saying eh? He's got this fear of being left.'" Page 29 line 19

Mother 1 graphically describes the physical effects she noted in her child when he was separated from his parents in the hospital. In the following incident, the child had been taken to theatre. When the parents were called to accompany the child post-operatively to the ward again, there was evidently a delay before they could get

access to the theatre suite. The desperation she felt to reach her child is apparent in the language she uses; she describes almost trying to break down the locked theatre suite door to remove it as a barrier between her child and his mother:

Mother 1 'The nurse, she's paging up, get them down here now, we were battering the door, even John the male nurse, he was battering the door to get us in.....and they were looking at his blood pressure, and it was just going higher and higher, and they were saying "Get his mum and dad, get his mum and dad" and the nurse said to them he knows his mother and father, stop and watch him as they come through the door.' Page 19 line 34

This account shows the physical effects of stress on the child, and her recognition of the ability of the parents to mitigate this reaction. This effect is also noted by Stoddart et al (2006) who note excessively raised pulse rate as one of the predictors of later post-traumatic stress. This recent study also found that children with parents unable to provide the necessary support and comfort during treatment were more likely to exhibit stronger post-traumatic stress symptoms after the injury.

Burn injury may have provided the most traumatic and dramatic occasion that the child and the parent were forcibly separated from each other, therefore the division of the parent/child dyad, and the behaviour and feelings prompted by this need further exploration and explanation in the light of psychoanalytical theories around parenting.

The affectional bond between parent and child, and its importance in developmental psychology is well explored in the literature. Some authors emphasise that the bond to the child's primary caregiver is secondary to the provision of nourishment (Fonagy 2001). Other work, however, based on the psychoanalytic work of Freud,

and continued by Anna Freud, Klein and Winnicott (Dally 1982), recognised that human infants were willing to interact with those who were not concerned with food. This social interaction must therefore provide for other needs than nourishment, such as meeting the need for safety and security to explore and learn about the world from a secure relational base.

Ideas on this formation of a secure bond, often referred to as attachment theory, have been vital in the growth of understanding of an infant's development. Bowlby (1907-1990) was instrumental in developing these theories during the twentieth century; others such as Ainsworth, Main and Bretherton have continued to contribute to the framework of attachment theory within developmental psychology (Holmes 1993).

The parents interviewed were aware that hospitalisation would increase the possibility of separation of parents and were deeply concerned that this caused high levels of anxiety in the child, in addition to their worry about the pain their child could be experiencing. My analysis of the data revealed that the parents made strenuous efforts to reduce the child's anxiety around the time of the injury firstly by attempting to contain their distress, but also by providing the child with a secure base to allow them to continue to develop in the time after the injury.

In his work, Bowlby emphasised the need of the child for the unbroken and secure early attachment to its mother, pointing out that if the child sensed that this separation was threatened they would demonstrate despair characterised by vocal

signs of distress. In the interviews, parents consistently describe their desire to be present as a means of preventing the child from becoming unbearably distressed.

On the simplest level, the parents describe that they provided reassurance simply by close physical contact. To the participants, this meant holding the child within the protective circle of their arms, suggesting a desire to defend the child from a strange and threatening environment. In this way, the parents were acting as insulator and filter, providing reassurance as well as expressing affection (Pringle 1992). However, the thoughts and feelings expressed by the parents suggest that the desire to hold the child close is more than simply being there to provide the child with reassurance and affection.

Some of the parents describe a desire to take the child's feelings of distress and pain onto themselves, internalising the feelings to help the child to cope. One parent interviewed described containing the pain in terms of almost feeling the pain herself:

Mother 8 'He was hurting so I was hurting' Page 13 line 45

This apparently simple statement encapsulates the idea that it is part of the role of the parent to contain the child's distress as well as their own. This idea is evident in the work of Bion (1993) who suggests that painful incidents must be internalised and dealt with in the light of previous experience. For the young child, that experience is lacking, therefore it can become the role of the parent to contain the distress felt by the child to make it bearable.

This requirement to help the child cope was interpreted by a number of parents as the need to remain strong in the face of adversity. Depending on the circumstances at the time of hospitalisation, parents expressed varying feelings of being in control of the situation.

Mother 1 'She {sister in law} said "How are you so strong, how are you so strong" and I said "We've got to be, we've all got to be strong for Lewis"' Page 13 line 43

The parents in this interview also report the medical staff supported their view of efficacy:

Mother 1 'It was even the surgeons when they came in during the night to him "Youse have been really really brave" Page 13 line 46

Other parents seemed less certain in their role as strong advocates for their children, and expressed a lack of confidence in demanding that they were present when the child was given treatment. This meant they were unable to contain the child's distress during treatment, and may well have contributed to their expressed feelings of helplessness.

The parents interviewed seemed also to be well aware of the need for their presence to provide a secure base (Bowlby 1980). This idea was advanced by Bowlby as part of his theory of attachment, where he sees the parents as needing to provide a consistent presence in the child's life. This presence, which he accepts will not always be physical, provides the child with a means to explore safely, but also return for comfort and support. This awareness seems to be particularly pertinent when they speak of the time after the injury. In the interviews, parents often describe clingy behaviour, with the child reluctant to play or sleep alone, and the parent unwilling to

let the child explore the environment in case they became injured. The parents identified themselves strongly as the secure base, but seemed very reluctant to allow the child to explore, perhaps because this exploration had previously resulted in the child becoming injured.

This identification of the parent as the source of safety and security is also important later in the analysis of the interview data, as parents discussed their transformation from wishing to hold the child to protect them to feeling impelled to acting in a guarding role to prevent further injury occurring.

4.6 Intentional holding

With the initial crisis over, the parents then seek to re-establish themselves as the primary responsible person for that child. This view is echoed by this professional mother of two describing her feelings on the way to the hospital when she heard about the burn injury:

Mother 4 'But I was anxious to get there and see him cos I was his mum, and he wanted me (laughs).' Page 2 line 17

The recognition of the perceived pre-eminence of the role of the mother while the child is in hospital is an important element in this and other research. In Hays' (1996) analysis of the concept of 'intensive mothering' the story of a mother refusing to leave her child's side in the hospital is given as the first example of the phenomenon she explores in detail in her work. According to the author, the mother she describes refuses to leave the child's side even though her life is not actually in danger. Hays

(1996) explains that, to the mother, only her presence was acceptable, no nurse or other relative would be adequate. The quotation from Mother 4 in this research echoes this, in its recognition that although the child had other relatives and professional carers present he would be waiting for and needing the presence of his mother.

The parents interviewed often seemed to be eager to provide evidence of the child needing them to be nearby, wanting them to be close. This seems to have two elements; the first is that the mother seeks to supply evidence that the child has somehow 'forgiven' them for allowing the injury to occur. The second element seems to be that the mother wishes to demonstrate her unique power by keeping the child within the protective circle of her arms, challenging the perception of the health professionals that she has failed in her duty to protect the child. In the eyes of the parent, the child's proximity seeking behaviour offers validation in the eyes of the professional.

As long as she has the child physically with her, appearing to be dependant on her presence, the mother has power in a situation where she feels her identity is threatened. This idea echoes that of Rich (1981:67):

'Yet the helplessness of the child confers a certain narrow kind of power on the mother everywhere, a power she may not desire, but also often a power which may compensate her for her powerlessness everywhere else'

It is notable that a number of the parents emphasise the child becoming more unwilling to separate from them following the injury. On the surface, this would

seem to be a natural reaction to the trauma of the injury and subsequent admission. However, the emphasis placed on this by the parents suggests they possibly wished to demonstrate that the reaction of the child was an overt vindication of their ability to parent.

Many of the parent's responses echo this; the exception to this was the one participant where the parent was not present when the injury occurred. In this case, the parents describe in detail the fact that their daughter was happy when they weren't with her. This response seems unusual, so is quoted at length:

Mother 3 'She was a different person when she came out, the staff were that good with her. I think the break from us, she never used to sleep, I couldn't stay over at night-time cos they did give me a parent's room, but Scott (father) couldn't get there. I'm very insecure on my own, so I said I'm just going home with Scott there and I'll come back in the morning Scott couldn't stay over, but she wouldn't let me either, she wouldn't go to sleep until we actually left.' Page 11 line 24

This seems to demonstrate that the parents considered the lack of anxiety demonstrated by the child in her parent's absence to be a positive attribute. This may be simply an appreciation of the quality of the nursing care given, but it is in such marked contrast to the feelings explained by the other parents that it is tempting to suggest that the parents did not feel the need to demonstrate the child's desire to have them near to vindicate their parenting. They were not present when the injury occurred, therefore could not be blamed. It is certainly evident that the parents are quite willing to admit that the child settled better without them being present, in fact they even say she would not allow them to be present, as evidenced by the

expression ‘but *she wouldn’t let me either*, she wouldn’t go to sleep until we actually left.’ (emphasis author’s own)

4.7 Conclusion

My analysis of the evidence seems to suggest that although the instinct to hold the child seems at first sight to be a simple reaction to comfort the child, it is in fact highly complex. The initial instinct to hold the child in the protective embrace of the parent demonstrates a desire to ensure professionals make no mistake on who has primary responsibility for the child. Those parents who were able to maintain this proximity also seemed to express more of a feeling of control, whereas those who felt helpless and disempowered by the hospital system expressed feelings of being compelled to let the child go.

In addition, parents describe the behaviour of the child as demanding the proximity of the parent. In some cases, parents seemed to see this as evidence that their child had ‘forgiven’ them for allowing the injury to happen, but also provides vindication of their parenting ability.

In the next chapter I will discuss the next stage of parental adaptation, where parents describe their need to ‘guard’ the child.

CHAPTER 5

'WE WRAPPED HIM IN COTTON WOOL' GUARDING - THE SECOND STAGE OF PARENTAL ADAPTATION

5.1 Introduction

In the previous chapter, the descriptions of how the parents felt compelled to hold their child close; keeping their son or daughter physically near to comfort the child and to maintain the family unit were analysed. As discussed, this seemed to be a response most often described in the days immediately following the injury, especially when the child was in hospital. The children's ward is an environment where the parents appear to feel that their identity as a family and efficacy as parents are under scrutiny, as well as a place where they feel an instinctive need to comfort and console the child's distress by their physical presence. This was particularly true while the child was undergoing treatment or surgery.

During the interviews, the participants went on to describe their feelings and actions after discharge from hospital, when the child was at home. In many cases, although the child had left hospital, burn treatment continued with the child attending the specialist children's hospital as an outpatient. This appeared to be a challenging stage for the parents because they considered their child had moved out of the perceived safe environment of the hospital. Although parents found their child's admission to hospital was often difficult and distressing for the family, to a certain extent they felt the child was separated from the dangers of the world outside, with the task of keeping the child safe shared with the professional healthcare staff. However,

parents were often expected to continue with the burn treatment at home after discharge. This was felt to be an added responsibility for many parents, with some participants concerned about the dangers of infection, and some also worried about the practical aspects of care.

The change involved in moving from the perceived safe environment of the hospital back into the environment where the child had originally been injured appeared to prompt the participants to move onto a second stage of parental adaptation. This stage, which I have named 'guarding', describes the time when the parents seem to express an overwhelming desire to keep the child safe at all costs. There is also an evident wish to take responsibility for ensuring that the injury treatment is effective at home. For many parents, the 'guarding' role seems to have become as overwhelming an imperative as the 'holding' instinct immediately following the injury. For the parents interviewed following their child's injury, the instinct to guard the child from experiencing further injury would seem to be very natural, especially as a number of parents express shock at how quickly and easily the child became injured in the first instance. However, it became evident from interpretation of what the parents were saying that the guarding theme was much more complex than might first be assumed.

The following chapter is first concerned with a discussion of the views of the parents on the impact of their role in ensuring the safe and effective continuing treatment of the burn injury, then with an interpretation of the complex themes revealed during

their conversations regarding the time immediately following their child's discharge from the hospital.

5.2 Emergence of the guarding theme - continuing treatment at home

Treatment for burn injury is not confined to that carried out in hospital (Jenkins and Stanwick 1991). For all of the children described in this study, some on-going treatment for the burns had to continue in the home environment. For some, this occurred during outpatient visits to the burns clinic, for others the parents became deeply involved in the day-to-day care of the injury.

In the interviews, parents expressed views confirming that they took this responsibility very seriously. For some, ensuring that the treatment instructions were followed exactly was hugely important; these parents demonstrated a belief that their treatment techniques could have either a positive or negative effect on healing of the injury. Parents described at length their efforts in ensuring that their child was protected from infection and given the correct treatment at home. Their discussions on these efforts once back home were the first time that the 'guarding' theme could be identified.

For Mother 1, making sure that her son was given all the treatment prescribed for him at home was vital in helping to reduce the visibility of the scar as much as possible:

Mother 1 'I think that was why we emphasised so much we will do bandage changes, you will wear your cream and your silicon jelly so we know whatever it ends up like we done the best we could.' Page 34 line 29

In this extract, the mother demonstrates an understanding that the long term appearance of the scarring was uncertain, but that she needed to know that, as parents, she and her partner had done 'the best we could' by ensuring that the correct treatment was carried out.

As well as feeling responsible for carrying out the right treatment, other parents seemed to worry that their actions might have a negative effect on their child's treatment. Mother 6 was faced with the situation where the bandages on her son's injured arm had slipped. She was concerned that by removing the bandage she risked jeopardising the treatment, but felt she had no choice:

Mother 6 'And I thought well I can't leave that..... Cos then you think if it was infected and you were to blame cos you took the bandage off but fortunately there was no infection, no repercussions from that.' Page 9 line 31

Her concern was clearly that by exposing the injury, she risked it becoming infected. Her comment reveals if the wound had become infected, she felt that it would have been her fault. In fact infection did not occur, but her use of the words 'blame' and 'repercussions' indicate that in some way she felt she would be judged if the injury had not healed.

The concern that the parents would be under scrutiny in their efforts to care for the injury at home was also reflected in the comments of the parents in Interview 9. Following initial discharge from the specialist hospital, their one-year-old son

developed a high temperature. This led to them attending the local primary care out of hours service. Their comment about their feelings on the way to see the locum doctor reveals their deep anxiety:

Mother 9 'And we sort of said on the way down that we'd been sort of playing at being parents with Tom (the older, uninjured child) the last five years, this is really serious stuff. This is the real thing' Page 6 line 12

Their statement about the seriousness of the responsibility they had is powerful. The expression 'playing at being parents' in relation to caring for their older child is in contrast to their comments 'this is really serious.....this is the real thing'. The latter statement reveals their feelings that caring for their burn injured child was a challenge to their abilities as parents.

The concern about the responsibility of caring for an injured child was also reflected in the views of Mother 5. A very young woman, whose lengthy interview revealed that she apparently lacked confidence in her abilities to parent, Mother 5 described her feelings about coming home:

Mother 5 'Oh, I just, I was just so glad that she was home, but in a way I was (pause)...it's just different in the hospital, you've got everybody there if anything goes wrong'. Page 9 line 39

Although she failed to verbalise her feelings, it was clear to the interviewer that she felt worry about caring for the injury at home. Her comment reflects a feeling of isolation and concern at not having support and information readily available.

It is significant that a number of parents interviewed expressed concern about their ability to care for their child once they had left the hospital. It seems clear, however,

that for some parents lack of information and support may have contributed to feelings of anxiety experienced immediately following discharge.

Other burn injury literature has recognised the importance of the correct care provided by parents once the child has gone home (Jenkins and Stanwick 1991, Blakeney et al 1990), however when undertaking a survey of the discharge education programmes undertaken by burn units in the United States, Jenkins and Stanwick (1991) found that programmes of mixed quality and effectiveness were provided. They suggest that this was due to lack of time and appropriate educational materials. The comments of the parents interviewed in this thesis confirm the importance of this information.

Once the child has left hospital, parents are then faced with the task of mothering or fathering their child with a new understanding of vulnerability, and a new imperative to protect the child. Their descriptions of this adaptation have allowed the development of the guarding stage of parental adaptation, which will be explored in the rest of this chapter.

5.3 Guarding – the second stage of the parental adaptation model

The identification of the ‘guarding’ stage can be divided into three themes:

- guarding from injury
- guarding from the environment
- guarding the child from the world

The first theme, 'guarding from injury' could be identified when the parents describe in detail their attempts to keep the child physically away from perceived danger. For a number of the participants, this involved descriptions of the parents preventing the child from engaging in normal activity because of a fear that this might lead to injury. This was, for many parents, complicated by the concern that further injury may lead to judgements being made of their ability to parent.

The second theme is 'guarding from the environment'. Here the parents discuss their sudden raised awareness that the environment, including their home, presents significant dangers. The participants disclose feelings of overwhelming responsibility to ensure that their child is in a safe environment, and reveal how their experiences have affected their views of danger.

The third theme is a development of the second. Following the injury, many of the participants expressed a belief that children were vulnerable due to danger in society in general. Experiencing injury and seeing the situation of other parents and children seemed to open the eyes of some of the participants. This leads them to express views that children in general are vulnerable, special and require extra care. The fact that their own children had required hospital treatment seemed to increase their belief that their child needs extra protection from the world. I have therefore named this third theme 'guarding the child from the world'.

5.4 Guarding from injury

Once the child had been discharged from the safe environment of the hospital, parents were faced with the fact that the family were back in the home. For some of the families, this was the place where the child had been injured, so returning was difficult. Some of the parents described this difficulty very strongly. For example, Mother 2 referred to herself as desperately anxious that her child might be injured again:

Mother 2 'I was a nervous wreck for a few weeks after that 'Don't hurt yourself, don't hurt yourself' Page 7 line 6

The nature of this comment where she repeats the instruction for her child not to hurt himself underlines her description of the anxiety she was clearly feeling.

Repetition to underline strength of feeling was also used by another parent. In this case, their son had been burned by spilling boiling water from a saucepan.

Mother 1 'For a first wee while we kept saying 'Dinnae (don't) go into the kitchen, there's boiling water in the kitchen and you got burned with boiling water, dinnae go into the kitchen because you got burned in there' Page 30 line 10

The parents interviewed were very clear on the duty that they felt they had to protect their children from further injury. Their experiences of injury meant that they felt this duty to be of enormous importance, but the participants interviewed recognised that watching over the child is a responsibility undertaken by all parents to a greater or lesser extent. For example, Mother 2 describes very clearly the imperative to guard and protect the child:

Mother 2 'No, it's an automatic thing, you're a parent and you have to look after this child, and you try not to let them get hurt. And I understand you can't watch them 24 hours a day, you can't protect them from everything but it's your job, isn't it? You're looking after that kid, you've got to make sure it's safe and nobody wants their kid to get hurt' Page 12 line 18

It is significant that she describes the obligation to protect as both 'automatic', indicating she feels it to be instinctive, but also as a 'job', implying she feels guarding is something morally expected by society as part of the role of a 'good' parent.

Protecting a child from danger and preventing injury is mentioned by a number of authors as basic to the task of being a 'good' parent. Hoghughi and Speight (1998), in a paper suggesting parental support as a measure to reduce anti-social behaviour, refer to protection from danger as a vital component of parental care, and suggest that failures in this element contribute to breakdowns in the parenting process.

In a discussion on the challenges of parenting in a pluralistic society Gross (1996) suggests that parents in all cultures have the goal of keeping their children safe, as well as providing them with strategies for economic survival in adulthood and transmitting cultural values. She describes these goals as hierarchical, so if one is threatened the others become less vital. The example given is that of living in a violent society, where the cultural influences surrounding the family will force 'good' parents to focus their efforts on keeping their children safe.

Cultural influences on ‘good’ parenting were also mentioned by Sidebotham (2001), who interviewed sixteen parents who had participated in the large Avon Longitudinal Study of Parents and Children. The interviews covered a number of aspects relating to cultural factors imposing on their ability to parent effectively. The results indicated that safety was a constant preoccupation for most of the parents interviewed, and there was recognition that this resulted in parents creating limits on their child to prevent injury. For these parents, who mentioned specifically that they were now unable to allow children to play independently outside the home, there was an understanding that the cultural perception of danger was so great that society imposed a duty on parents to restrict their child and prevent them from undertaking the normal activities of childhood to keep them safe. One quotation from Sidebotham (2001:476) indicates these views well:

‘Kids aren’t allowed to be kids anymore. Kids can’t go out to play. They cannot go out to play, you can’t allow your child to go out to the park on their own. I wouldn’t let my kids go to the park on their own. Cause it’s not safe’

The perception that parents are forced by society to make greater and greater efforts to keep their children safe is of particular importance when applied to parents living in unsafe environments due to economic or social factors. Raver and Leadbeater (1999) found that the inability to maintain a safe environment for children was a significant stress factor for low-income women. Roberts et al (1995) in interviewing parents living in a deprived urban area of Glasgow identified that parents experienced very high levels of anxiety. The interviewees felt that they were expected to keep their children safe in an environment with recognised poor housing.

For the parents interviewed for my study described in this thesis, there was additional pressure. They were forced to live through the distressing experience of seeing their child receiving medical treatment for an injury. However, there was the extra factor that parents felt cultural pressure to ensure that injury did not occur again. It is therefore understandable that they should initially express an overwhelming instinct to watch over and guard their child.

5.4.1 Hovering

For some of the parents this took the form of physically holding the child to prevent them from being exposed to any risk at all, even to the extent of preventing them from moving around independently. Some parents describe hovering over their children, constantly warning them against putting themselves into danger. By holding the child or hovering over them, the parents were, perhaps understandably, reacting to the fact that they had nearly 'lost' the child as a result of the potentially life threatening injury. However, the parents also seemed to be demonstrating an acute awareness of the need to be seen to be protecting the child. This has parallels with the discussion on holding in the previous chapter, where parents described holding the child to demonstrate their responsibilities as parents.

One mother describes the behaviour of her husband in caring for their two-year-old child following the injury:

*Mother 7 ' I think we're both more wary, safety wise and everything.
Craig's more protective, a lot more than I am if he takes him out
anywhere, and he's not allowed out by himself. At one stage he was*

taking him out and wouldn't put him down and I was saying "Put him down!"'' Page 12 line 27

In this extract, it appears that one parent, in this case the father, was still trying to 'hold' the child but in this case to protect him from danger and prevent injury. The mother had moved on, and although she was aware of still 'guarding' the child (she uses the word 'wary' to indicate her heightened sense of danger), she felt that the child needed to at least move freely if only under close supervision.

Another parent vividly describes her actions for example, constantly nagging at her children to prevent them getting into danger:

Mother 2 - 'When we were out I used to try and sit him in a buggy, so he wouldn't hurt himself, and it made me terrible for like weeks after it, but now I'm just more aware of dangers around the house..... Constantly at them, don't fall, don't climb.' Page 14 line 3

This quote describes the different elements of 'holding' and 'hovering' very well. The mother's first instinct to hold the child was satisfied by sitting him in a buggy, where presumably he was strapped in and unable to move himself independently. She then explains how she is 'constantly at them, noting danger and warning her children not to be adventurous and put themselves at risk.

5.4.2 Parental supervision as value judgement

The role of the parent in watching over the child to prevent injury is frequently discussed in childhood injury literature. Health education interventions to prevent scald injury, for example, have frequently been focused on behavioural modification

of parents (Corrarino et al 2000, Jeffery et al 2000, Gaffney 2000, Hunt et al 2007). Several studies have, in general, concentrated on interventions aimed at encouraging parents to supervise their children more carefully when they are aware that burn injury risks are present. For example, Gaffney (2000) and Jeffery et al (2000) devote a considerable amount of effort to describing the danger posed by hot irons and bowls of boiling water to heat milk. Both authors suggest that behavioural change on the part of the parent is the most effective way to reduce the danger. Hunt et al (2007:37) clearly identify negligence on the part of the caregivers as the key issue in spill scald burns, and claim that behaviour modification is unlikely to be successful when 'people forget' to keep hot liquids out of the reach of children.

Assuming that simply educating the parents to modify their behaviour or supervise their children more carefully implies a value judgement on the part of the professional that parents are solely responsible for preventing injury to their child (Roberts 1996). Ian Roberts argues that this judgement is flawed; he suggests injury prevention researchers make judgments on the value of parental supervision without having a valid means of measuring it. Because of this lack of empirical evidence he further argues that targeting parents with messages about increasing supervision can be interpreted as ideological statements: firstly because mothers are the primary caregivers, increasingly in one parent families, he suggests judgements made about poor supervision are directed specifically towards women; secondly that emphasising parental responsibility allows authorities to underplay their role in ensuring a safe environment by changing policy.

Helen Roberts et al (1995) also discuss child safety as having a complicated social value, with accident risks expressed in a way that allows society to evade its responsibility in ensuring child safety. If injury to a child can be explained by lack of supervision, being accident prone or as simply 'bad luck', policy makers can confine themselves simply to trying to educate parents and children on the means to avoid injury.

If, as Ian Roberts (1996) argues, parental supervision to prevent accidents is simply a myth, it is a myth that is pervasive in society. Certainly, the participants for this study reveal that they feel this responsibility even more keenly after their child had been injured, and seem eager to demonstrate that they have increased their supervision.

This view of parents of burn injured children contrasts with a study of parents of uninjured children in South Africa (Munro et al 2006). In their qualitative study of influences on childhood injury, a group of six parents were interviewed as part of a focus group. Other groups interviewed were made up of professionals. The parents did not identify parental supervision as a factor in injury, preferring to blame the environment or characteristics of the child. The professionals were more likely to identify lack of parental supervision as a risk factor. The authors suggested that this might have partly have been an unconscious attempt to attribute injuries to factors outside the control of the parents in order not to appear to be a 'bad parent'. However, the fact that this was a general group of parents, with no suggestion that

their child had experienced injury might suggest that they felt no particular need to demonstrate that they had increased supervision.

5.4.3 Professional scrutiny

This concentration on ‘proving’ good supervision of the child is an important factor in understanding the concerns expressed by the participants in the study reported in this thesis. Some of the parents interviewed mentioned deep concerns that they were under a lot of pressure to prevent their child from being injured again, because they had ‘allowed’ it to happen the first time.

Two mothers in particular vividly described their feelings of acute worry when the child was injured again. Mother 2 describes witnessing her son knocking his head on a piece of furniture, sustaining a scalp wound that bled profusely. For this family, the previous burn injury was investigated thoroughly as there was suspicion that it might have been non-accidental. Mother 2 found this experience extremely stressful, feeling that she was being accused of injuring the child herself and then lying about it. In the following extract, she is concerned that this might happen again:

Mother 2 ‘I’m not very good with blood, and I started getting panicky, “I need to get him to hospital but they’re going to accuse me of doing it.” Then Davie, my brother said “But I’m here to verify you didn’t do it” and I said “But they didn’t believe me, why would they believe you?”’ Page 6 line 46

Her reluctance to attend the hospital was clear, even though she had a witness that the injury was accidental.

Another parent also expressed concern that another injury would suggest she was not guarding her son well enough. In this case, the child had banged his head on a wall:

Mother 7 His head went up like a big tennis ball and my neighbour said I should take him to A&E just precautionary, and when Craig (father) told his mum she said 'You'll have to watch him cos they'll start taking notes in A&E' which made me feel really guilty cos it was just me here and I was annoyed.' Page 11 line 50

The mother here uses the words 'taking notes' to suggest that the family may be 'marked' by professionals. The use of the words 'It was just me here' is significant, as it suggests that the mother felt nervous that without another witness to the event, it could be suggested that she was failing to supervise her child correctly.

These examples show that the parents interviewed expressed understanding of professional scrutiny making judgements on their ability to protect their child from further injury. They also looked for health professionals, in particular health visitors, to provide proof that they were competent parents despite the injury. For example, Mother 2 felt very strongly that her health visitor could provide a judgement on her parenting ability because of a long-standing relationship:

Mother 2 '...and they didn't think to maybe phone the health visitor for advice to say what sort of parent is she, cos the health visitor knows me, they'll know about a lot of the, I'd seen the health visitor for a few years because I've got a lot of kids. I've got to know the health visitor quite well' Page 7 line 35

The theme of guarding from injury is focussed very much on the child; with parents describing placing themselves physically close to prevent exposure to danger, as well as being clear in recounting their efforts to supervise their children. This is understandable especially soon after discharge from the hospital, as they had spent

considerable amounts of time concentrating on the needs of a potentially seriously ill injured child. During the interviews, however, parents described their experiences as the family became more used to being back at home. These descriptions can be analysed to identify a further theme, guarding from the environment.

5.5 Guarding the child from the environment

The experience of seeing their child injured clearly led to a compulsion to protect the child from further injury, but the parents went on to describe in detail how they had undertaken to protect the child from the environment. Remarkably, they discussed the fact that the injury experienced had changed their view of children's vulnerability in relation to the domestic environment, where once they would have assumed that the home was a safe place, many of the participants describe having developed an acute awareness of dangers in the home. Some of the parents went as far as describing themselves as having become 'paranoid':

*Mother 2 - I think it's made me a paranoid parent, I'm scared that
Ryan will get hurt, but that's like the lot of them, not just Jack, at first
it was just singled out, Ryan' Page 13 line 3*

This parent is describing how the experience of her child's injury has increased her anxiety about the safety of all her children. She mentions that in the first instance, she was mainly anxious about the injured child, but implies that this worry has become more generalised to the rest of her children. This mother was also speaking over a year since the injury had occurred, and was still talking about being 'scared' that her children would get hurt. This impression of fear is also noted by Roberts et

al (1995), who found that fear of injury dramatically increased the stress and anxiety experienced by parents.

Roberts et al (1995) also noted that parents perceive there are often inherent difficulties in incorporating safety practices into everyday life. The parents interviewed for this burn injury study acknowledged that their child's injury made them more aware of the danger in the environment, but expressed the view that other factors get in the way of ensuring that there is always a safe environment for the child:

Mother 8—'But even when you're at home and practicing it doesn't always come to mind. You always think there's something there you could have done better, you could always have done it better but when you're thinking about it you're just thinking about the children, you're not always thinking there's a wire down there.' Page 12 line 42

The implication from this statement is that this mother felt that ensuring a safe environment was part of the 'package' of being a mother. She uses the term 'practicing' as her expression of the daily work of parenting. This idea has clear links with the concept of 'working it out' used by Rogan et al (1997) in their grounded theory analysis of early motherhood. For Rogan et al (1997) 'working it out' is used to express the idea that because women parent in a social context of little support or nurturing, they are forced onto their own resources. This results in women working it out as they go along, with the associated risks and possible failures.

For Mother 8 ‘practicing’ to be a parent involved keeping her children safe, but she recognised that there were many distractions. Other parents also discuss how the experience of injury has taught them about hazards in the environment:

Mother 3 ‘I was paranoid, but there are some things you can’t actually see with your own eyes until they happen.’ Page 18 line 41

The implication here is that the mother feels that she needed to have the experience in order to fully understand the injury risk. Another set of parents agree that experience of injury has changed them. They are very clear what seeing the after effects of the injury has done:

Mother 1 ‘I think you need to kind of be able to see what the after effect is, and what it can do, like dinnae leave a boiling pot on, and we DID.....But it wasn’t until we actually....now we can LOOK at what he’s left with, and we can see the difference and it sinks in.’ Page 32 line 37

The parents here were evidently convinced that it had taken the experience of seeing their child being injured and the aftereffects of this to really raise their awareness of how hazards in the home can lead to significant injury.

5.5.1 Learning from accident experience

During the interviews, parents were asked to compare their attitudes to safety before and after the injury. It became evident from the data that although parents saw safety behaviours as mainly ‘common sense’, there seemed to be a consensus that seeing a child experiencing accidental injury taught a valuable lesson about danger.

Grandmother 5 'It's made me think more about safety, it's sad that it takes something like that to understand. I mean, I've always been safety conscious, and Heather's dad, he wouldn't let her eat boiled sweets.' Page 17 line 8

This idea was expanded by the parents in Interview 3. They had not been present when their child had been injured, and although they expressed anger that the accident had occurred, there seemed to be a feeling that many dangers in the home occurred through ignorance:

Mother 3 'Aye, but you never learn until you get stung. That's what I say, there's that many things we all do over. How many times did I bring a jug of water here and it's just cos we've got an alcove that I put it up there?' Page 15 line 4

This extract seems to express the idea 'There but for the grace' which many parents will recognise. For Mother 3 there seems to be a realisation that the injury, which happened in a relative's home, could just as easily have happened in their own home.

Later in the same interview, the parents describe how hearing about the experiences of other families was a good way of learning about safety behaviours:

Mother 3 – 'New things come out all the time but you learn more from experiences round about you. You go to nursery, and you see the things that happen to the people at nursery' Page 17 line 9

Childhood injury prevention literature has noted the effect of accidents in raising parental awareness of injury prevention. The Morrongiello and Dayler (1996) study which undertook research in Canada to examine attitudes, awareness and beliefs regarding injury risk found that parents did not routinely think in terms of injury possibilities, and although they appeared knowledgeable about injury risk, these were

often not identified until the researchers drew attention to them. The authors concluded from their findings that parents do not routinely feel the need to engage in injury prevention practices unless motivated by an injury or near injury to their child or another child they knew. They described these as reactive preventative actions rather than pro-active or anticipatory actions.

This element of experience leading to knowledge was also an important, if possibly unrealised influence in one of the few randomised controlled trials of an injury education intervention. King et al (2001) identified a relatively large study sample of 750 children attending a hospital in Canada. As part of the study design, three groups of children were selected. One group had presented to the emergency department with an injury sustained in the home environment; children in the other two groups had presented with either an injury sustained outside the home or a medical illness. These two groups were combined, and then matched with children in the home injury group to act as a case control. The parents of all the children in the study were asked to identify the leading cause of death in children; 73% in both the home injury and the control group correctly recognised injury as the greatest cause of mortality. The parents were also asked to score their perceived ability of parents to prevent injuries or decrease accident risk. Both groups scored remarkably similarly, with scoring their ability to be 7 or 8 out of 10.

The authors indicate that both groups did have a good awareness of injury risk and preventability that was unaffected by the intervention, a home visit to discuss home safety. Therefore they suggest that the families were already vigilant in regard to the

safety of their children's environment. However, no comment was made on the fact that two thirds of the study group, including half of the control group, did have recent experience of their child being injured. This may have led to them being more likely to assume that they could – or should be able to prevent injury to the child.

5.5.2 Accidents – a chance occurrence?

The views of parents on the preventability or otherwise of accidents has made a significant contribution to the ongoing discussion in injury prevention circles on whether the use of the word 'accident' has a negative effect on prevention efforts. The conflicting views on whether the public genuinely believe that an 'accident' is purely a chance occurrence that could not have been avoided have been explored by a number of injury prevention writers (Bijur 1995, Girasek 1999, Evans 2001). Of particular interest to this research were studies undertaken by Evans (2001) and Girasek (1999).

In an attempt to find out if lay individuals do not engage in active injury prevention measures because of a belief in fate or chance, Girasek (1999) reported on a national telephone survey of nearly one thousand adults in the United States. The intention was to discover how the subjects interpreted the word 'accident', and whether this interpretation had an effect on their efforts to prevent injury occurring. The findings show that the largest number of respondents interpreted the word 'accidents' as 'not done on purpose' (Girasek 1999:23). The authors suggest that this attitude may be

displayed as a reaction to victim blaming, where the experience of injury is considered to be inevitably the result of fault. In particular, they raise the issue of negative attitudes to the parents of drowning victims, who are judged by some as incompetent and uncaring.

Evans (2001) undertook a randomized comparative study of 1823 health visitors in an attempt to discover if changing the terminology from 'accident' to 'injury' prevention affected their attitude to the usefulness of prevention activities. The author hypothesised that promoting the use of the word 'accident' led to a belief that prevention activities would be ineffective, as most events were due to chance. Conversely, using the word 'injury' would lead to the belief that prevention activities could have a positive effect, due to the assumption that an injury was generally preventable. The group of health visitors was therefore divided into two, with half given a questionnaire using only 'accident' terminology; defining accidents as 'unwanted events that are unexpected or unplanned' (Evans 2001:173). The other half was given a questionnaire defining unintentional injuries as 'injuries which are not deliberately caused by another person' (Evans 2001:173). Key issues within the questionnaire were attitudes regarding the preventability of various injury scenarios, victim blaming and the relative importance of accident/injury prevention in comparison to other parts of the health visitor remit. The study results showed little difference in the responses between the two groups, suggesting that changing the terminology from accident to injury does not have a favourable effect on the attitudes of professionals to their role in prevention activities.

Data collected for the study reported in this thesis also suggest that although parents have an awakening understanding of the preventability of further injury, they express a wish for the element of chance to be expressed:

Mother 6 'But there was no like reassurance, no 'Don't worry about it, it was an accident' and that kind of thing.' Page 7 line 44

This quotation suggests that in this case, the mother was looking for some form of exoneration from the professionals she was coming into contact with. If the finding of the Evans (2001) study does reflect that professionals do not take into account the element of chance in injury, then the experience reported by this mother does not seem surprising.

Some of the parents interviewed mentioned the health visitor's role in drawing their attention to dangers in the home environment. Two mothers in particular emphasised the provision of written material and the recommendation of safety equipment as important roles for health visitors:

Mother 5 'When I went to the health visitor to get her eight-month check, you get a booklet on safety..... Before Rachel was born I always used to go along to the, you know the safety things. And the booklets, see like 'Ready, Steady Baby', they told you about the safety aspects' Page 16 line 45....page 17 line 3

Interviewer 'So is it something that you automatically think about? Did you get safety information from your health visitor?

Mother 9 'Yes, we still have catches on everything and everything in the kitchen is magnetised to be shut and plug covers are in (laughs). We're very safety conscious, yes.' Page 18 line 23

Combes (1991) also found that parents had very specific needs in regard to health visitors helping them to maintain a safe home environment. They wanted health

visitors to make suggestions rather than be directive, reassure rather than undermine, and build up long term supportive relationships to help parents continue to keep their home safe as their child developed.

5.5.3 Coping with vulnerability

Having revealed the imperative to maintain an environment safe from injury risks, participants also discussed their feelings around trying to keep the environment clean and safe from any risk of infection. The youngest mother included in the study group explains with great vividness her overwhelming need to control and protect her child from the environment. In the course of the interview, she describes at length her experiences when her child had been admitted to the same hospital with a serious infectious disease. Although not connected to the burn injury, her experience coloured her view around being the parent of a child in hospital to such an extent that it is important that this is quoted:

Mother 5 'After she had meningitis, after she came out of hospital I got a bottle of disinfectant and I cleaned every wall. I kept thinking it was something I had done, because she'd had it. Everything had to be sparkling clean and I went through a terrible stage, cleaning, bleaching, hoovering. I'm still like that, I hoover six times a day, the first wee bit of dirt I see, I'm terrible.' Page 16 line 16

This mother clearly felt that she should be, as Rich (1977:53) states 'held accountable for her children's health'. Not only did she seem to blame herself for the child contracting the illness, but her emphasis on protecting the child through cleanliness, guarding her from the danger of dirt had continued. It is, however,

interesting that this mother does not see this as a virtue. She uses the word 'terrible' twice within two sentences, seeming to feel that her emphasis on housework was wrong.

The idea that children with health problems are perceived by parents to be more vulnerable to the environment is an element noted in discussion around the 'vulnerable child syndrome'. This was first identified by Green and Solnit (1964), who, in reporting on a cohort of children who had recovered from life threatening acute illnesses, noted that their parents continued to believe that their child was uniquely vulnerable, leading to difficulties in interaction between parent and child. In particular, parents displayed a tendency to overprotect their child, had difficulty in setting age appropriate limits and were excessively concerned about their child's health. A number of authors have developed these theories in relation to prematurity, cardiac abnormality and chronic illness (Kerruish et al 2005, Teti et al 2005, Lok and Menahem 2004, Anthony et al 2003). Research specifically linking post-injury care and perception of child vulnerability has been difficult to identify, however it could be suggested that the parents of burn injured children are constantly reminded and therefore concerned about vulnerability because of the long drawn out treatment schedule as well as visible scarring. It is possible to draw links between the feelings of these parents, and the feelings of the parents of children who are undergoing treatment for congenital abnormalities affecting their appearance.

Warschausky et al (2002) examined the parental health related perceptions of a group of fifty-four children and adolescents attending an outpatient craniofacial anomalies

clinic in the United States. The primary care giver of each child was asked to complete the Child Health Questionnaire. Results indicated that the parents were experiencing significant health concerns about their children leading to high levels of stress, but were unable to identify exactly what these health concerns were. The authors suggest that this may stem from a belief that children with craniofacial abnormalities are especially fragile or vulnerable, even if parents are unable to analyse specifically what leads to this belief. It is possible that the potential for psychological distress because of unusual appearance may lead parents to believe that their child's physical health is fragile. Acquired burn injury leading to long term scarring will also change the appearance of a child, and it will be seen in the next chapter that this change from the 'perfect child' is extremely challenging for the parents in this study.

The imperative to keep the environment clean and safe from infection is also mentioned by Miles et al (1998) in a study looking at the concerns of the parents of prematurely born infants. In this study mothers reported feeling especially protective because of the need to protect their child from infection, but the feeling of over protectiveness appeared to continue to the child's third birthday, clearly connected to the child's prematurity, and the resulting protracted medical intervention. The view that the parents seemed to be expressing was that they didn't want to see the child going through any more adverse circumstances, because they had already gone through so much.

It was evident from speaking to parents involved in this study that they were very aware of the need to guard their children from the environment. There is an understanding that the environment poses an injury risk to the child, and a very clear assumption of responsibility to protect their child. However, there was consensus from a number of the parents that it took an injury occurring to really demonstrate the vulnerability of children, and this led to significantly raised anxiety levels.

5.6 Guarding from the world

Interpretation of the interview data has allowed me to identify that parents felt a strong need to protect their children both from further injury and the home environment. However, analysing parental narratives also revealed that the impulse to guard the child did not seem to be confined only to protecting them from injury. In the interviews, parents vividly describe an acute awareness of the vulnerability of children in the world. Some attribute this to natural parental instinct warning them of danger all around:

Mother 6 'I think once you have a child you just put your fears into like practice cos you're always thinking about what could happen to them if he ran into the stream or if he ran out into the road you know that kind of thing. So you are very much aware of the danger in life I think.' Page 12 line 37

This quote demonstrates the feeling that other parents also identify; that the world is a hazardous place with its true dangers only appreciated through the vulnerability of a child.

Another parent describes vividly that she was almost expecting something to happen, a feeling of impending dread. Her comment reflects her feelings about the vulnerability of children:

Mother 3 'It's like, I was waiting on something like that happening. I was always waiting waiting, what if this, what if that, then it happened.' Page 9 line 26

The use of the words 'what if this' suggests that she was aware of a constant feeling of anxiety that something might happen to her child, the burn injury seemed to fulfil her fears.

5.6.1 The perception of the world as a more dangerous place

There is much current evidence which seems to support this parental view. The Guardian newspaper reported a survey in which they asked a random sample of 1050 adults across the United Kingdom about life for children. 79% agreed that life was more dangerous for children than it used to be, 57% felt that children were now more at risk from paedophiles than they used to be (Guardian/ICM 2000).

This concern can be seen as one of the most significant cultural factors affecting parenting in recent times. Sidebotham (2001), when interviewing a group of sixteen parents, noted that participants were deeply concerned by worries about traffic danger and abduction. He reported that parents felt that these worries were restricting the freedom of children.

Other writers have expressed concern that parental anxiety about safety is restricting the lives of children. In particular, Guldberg (2007) writes that although parents are concerned about allowing their children to play outside the home, this reluctance is as a result of a general societal preoccupation with risks to children. She claims that safety charities foster a climate of child vulnerability by constantly reminding parents of the danger of accidents. As a result, parents are losing sight of the resilience of children, and not allowing them to learn to handle risk.

In a book subtitled 'Motherhood in the age of anxiety' Warner (2006:194) describes this generalised concern about children's safety as 'ambient anxiety'. She asserts that the media, with its preoccupation on reporting situations where children are in danger, perpetuates the myth that parents only have themselves to rely on to protect their children and only by exerting rigid control over the environment can this be achieved. She quotes one expert as saying:

'If people point at you when you walk down the street and say 'Look at the neurotic parent'...then and only then are you being careful enough'

In a climate such as described by Warner (2006) it hardly seems surprising that parents whose child has experienced an injury will feel guilty and responsible if it is considered that they allowed the control over the child's world to slip.

Furedi (2002), in his book 'Paranoid Parenting' has also written about the current panic about child safety. Again discussing the role of the media in reporting on child abuse or abduction, he suggests that serious incidents where children are at risk are always accompanied with questions about the presence and effect of the parents.

The long-term effect of this, he suggests, is that the public will come to assume that parents are morally culpable for any misfortune affecting their children. This leads to considerable pressure on parents to demonstrate that they are fanatically committed to policing their children.

The overall effect of pressure is that parents are encouraged to take a precautionary approach to parenting; physical injury to a child is no longer accepted as part of growing up and it must be prevented at all costs. He claims that today's parenting style sees safety and caution as intrinsic virtues; it has therefore become a moral imperative to protect one's child from danger.

The view that the world is a more dangerous place for children is not supported by the evidence. In Scotland, the mortality rate for children under fifteen has halved over the last twenty years (ISD Scotland 2006). The report of the General Registrar of Scotland in 2005 also indicated a steady decrease in the numbers of deaths from injury and poisoning since 1911 (GROS 2006).

5.6.2 Children at risk from adults

Another factor mentioned by the parents interviewed for this research study was that of parents deliberately harming their children. For at least one key informant, this was connected with the close questioning she experienced in the hospital about the circumstances of her son's injury. In the following quote she expresses her resentment about the way she was treated:

Mother 2 'It makes me feel really really angry because one instance I see a wee lassie, I think it was in London, I think there were 20 odd visits to the house, social workers, health visitors, police even and they got to kill that kid, and nobody stepped in. I believe if something's going on they should step in, but they did with us, why don't they do it with everybody. And that wee boy, I think it was in Glasgow, the mum and the boyfriend left him for 2 days in a cold room and never fed him, he died as well. How did they get away with treating a wee boy like that?' Page 6 line 45

Her anger is clear, but her knowledge of two recent and well-publicised child protection cases is also significant. Her comment seems to indicate that she feels the wrong people come under suspicion, but those who do abuse their children are allowed to 'get away' with it. A later comment reveals she felt that the professionals were accusing her of harming her child without a full understanding of who she was and the quality of her parenting:

Mother 2 'They could have done a background check to see if I'd beaten up any my kids before they'd started to assume, why I'd done it to him know what I mean? They should check before jumping in and accusing people of doing things they haven't done.' Page 7 line 38

The use of the word 'assume' suggests that she felt judgments were being made on her motives for causing injury to her child, signifying that she felt that she was being stigmatised as a bad parent without the full facts being known.

Another set of participants mentioned assumptions being made about who is likely to harm their child. In this case, they felt that other parents were being stigmatised because of their personal situation:

Mother 1 'They put you into a category and that's what I didn't like. I got really edgy, don't put us into this category until you know the situation, ken (know) what I mean. Anything could have happened to them or they could be doing the best they can because of where they

live, cos they're not married, ken what I mean, but you've got this stigma.' Page 38 line 39

Her view, that people are stigmatised because of their marital circumstances or where they live seems justified when reading relevant literature on non-accidental burn injury. Robert et al (2007:773) state quite categorically that:

'Maltreated children live in poverty-level households headed by a young single parent who has two or more children'

Presumably then, they consider it impossible that a child not from this situation could be maltreated. Mother 1 appeared to recognise this quite readily:

Mother 1 'With his mum and dad coming in I think they got the impression that he hadn't been left, so it was a genuine accident. I think that was why we never got to see the social workers, it was just the nurses eh?' Page 37 line 30

Her implication is clear: that both parents were around, interested and visiting, meant that the injury must have been an accident.

Furedi (2002) describes recent awareness campaigns in Britain warning the public that children are at risk from their parents, especially those who are parenting under pressure. He is of the opinion that constant reminders that children are more frequently abused by those who are close to them has led to a wide mistrust of parents, leading to suspicion that injury may be non-accidental.

Parents are faced with the task of keeping their children safe in what may appear to be an increasingly hostile world. If the prevailing culture of that world is that children are vulnerable and even parents cannot be trusted to look after them, it seems unsurprising that the parents interviewed in this study express deep concern

about their child's welfare and safety. For Mother 6, this concern is reflected in this comment:

Mother 6 'I think you just hear so many stories as well of children disappearing out of gardens, things like that you know and there was one time he's gone round and he was sitting on the bucket at the side of the house and of course I'd come out and I thought "Ahh" and he was sitting up there just watching the world go by and I said "Don't do that, I can't see you round there, I want to have you out here where I can see you"'. Page 12 line 13

Being able to watch her child is, clearly, essential in order to protect him from a dangerous world.

5.7 Conclusion

In this chapter, three elements of 'guarding' the child have been described. The first 'guarding from injury' was centred upon the child, with parents describing how they attempted to shield the child from danger. There was also discussion on the parent's perceived responsibility to make sure that the injury itself was cared for, and protected from further complications.

The second theme, guarding from the environment could be identified from discussion around the parent's thoughts and feelings at the time of returning to the home environment. The issue of learning from experience was raised, as was the source of the information used to make the environment safer.

The last theme, guarding from the world, was concerned with the vulnerability of children in what appears to be an increasingly dangerous world. Cultural changes

leading to caregivers trying at all costs to control the environment around the child, especially as protecting children is now seen as a moral imperative. Some of the participants also identified loss of trust in the ability of parents to keep their children safe, especially in stressful circumstances.

This task of protecting the child from a potentially hostile world leads to identification of the third part of the parental adjustment, 'defending'. It is with this final theme that the next chapter of this thesis is concerned.

CHAPTER 6

'IT'S NEVER GOING TO HOLD YOU BACK' DEFENDING - THE THIRD STAGE OF PARENTAL ADAPTATION

6.1 Introduction

The instinct to protect the child from injury is an accepted part of parenting for most mothers and fathers (Sidebotham 2001, Hoghughi and Speight 1998, Gross 1996). However, as can be seen from the previous chapter, for the parents interviewed in this study safeguarding their child had become an imperative. Interpretation of the data provided in the interviews resulted in the identification of the theme 'guarding' to explain how the parents tried to protect their child, first from further injury, then from the dangers in the environment, and finally from the threat posed by the world in which the child must live.

Later in the interviews, parents tended to discuss the issues that they and their child were likely to confront in the longer term. Their views and opinions contributed to a final theme, which I have named 'defending'. Although defending can be identified most readily in the later stages of family adjustment, elements of this theme are a central part of the protectiveness that the parents described earlier in the interviews and which has been analysed in the two preceding chapters. As such, it can be seen as part of the process of adaptation experienced by the families featured in this study.

This final theme has two elements. The first, defending the child and family from shame, concerns the parents wishing to help both their children and themselves come to terms with the reaction to the physical effects of burn injury scarring by the world

outside the family. Participants discussed their very real concern that their child might feel ashamed and embarrassed about their appearance in later life. In discussing this, parents also talked about coping with their own emotions when others saw their child's scarring, and how this affected their feelings of guilt and shame over how their child became injured. The following chapter initially is concerned with the views of the parents on how they dealt with the issue of the child's physical appearance, and how the family adapted to the change in their relationship with people outside the immediate family.

The latter part of the chapter concerns the second element in the defending theme. Subtitled 'defending the child from victim hood', it contains an interpretation of the parent's discussion on their views regarding the identification of their child as a burn injury 'victim'. The participants discussed their feelings about their child's future and how they would manage to integrate and be part of society when they may feel socially uncomfortable because of their unusual appearance.

6.2 Defending the child and family from humiliation

During their discussions, the parents talked about coming to terms with the physical appearance of their child. This included information on how they coped with seeing the scars from the burn injury, as well as what happened when their child's burn injury was visible to those outside the immediate family. Their discussions had two elements, the first was concerned mainly with their attempts to defend and protect their child from embarrassment because of their changed appearance. The second

element was to try and defend themselves from humiliation at what they felt to be clear evidence that they had let their children down by allowing them to become burned.

A number of the participants mentioned the trauma experienced when they realised that their child's appearance had radically changed. One very young mother described how she felt at having to look at her child's injury constantly, especially when she was naked:

Mother 5 'It's having to bath her and look at it all the time, to know that she'll always be scarred, when she goes to school' Page 17 line 41

Her words echo her recognition that the scarring was permanent; she not only mentions that she knows that the child 'will always' have scarring, the reference to school underlines her knowledge that her child's appearance will be significant at major life milestones.

Mother 1, who recounted an exchange with her son's plastic surgeon about his facial appearance in the future, highlighted the recognition that a child may be affected by scarring throughout life:

Mother 1 'I was years ahead of myself and I said "With this burn thing under his chin, will he be able to grow a beard?", and I thought that sounds really, eh? He looked at me and he thought "A beard?" And I thought oh, and I could see him thinking "Strange mum" and I thought "Where's that come from?" and I looked and I thought "My god, how embarrassing".....And it was funny, cos Mr A. said "Do you know something, I cannae (can't) answer that", and we laughed and it was that awkward. He says the hair follicles might be damaged, only time will tell.' Page 24 line 36

This exchange shows clearly that parents have an acute appreciation that the burn injury scarring will have a long term and significant effect on their child's appearance in the future. Even though this mother's son was still only six, she was plainly looking ten years into the future when he would start to shave. Her opinion that the plastic surgeon appeared to think this was a strange question to ask suggests that professionals may be unwilling to discuss long-term outcomes with parents.

The realisation that the child may always look different in the future means that parents have to come to terms with the fact that they have 'lost' the child they had before the injury. The change from the 'before' child to the 'after' child is described very well by the parents interviewed in Interview 3. Their one-year-old daughter had sustained significant scalds to her back, leg and foot from a jug of boiling water. Earlier in the interview the parents had discussed at length their difficulties in seeing the burn injury. In this extract, the mother talks about the moment when she and her partner, having left the room during a dressings change, returned to see their daughter without bandages on:

Mother 3 'It's like the day we went through and we came back, and she didn't like have any bandages on, it was like "My god, Chloe, look at you, you were so perfect when we made you"' Page 11 line 20

This poignant quotation illustrates well the realisation that their child was very different from the way they remembered her before the injury. The brief statement 'you were so perfect when we made you' seems to encapsulate the grief that the parents felt at having 'lost' the perfect child they had created.

As well as being aware that the child looks different, parents also recognise that the child's life, and the way that they would parent the child, has to change.

Other authors have recognised this process of adaptation; however much of this literature is written on the subject of parents whose child is born with special needs. Barnett et al (2003), in describing a group intervention programme for parents of children with special needs, discuss at length the process experienced by parents when given the news that their child has special needs or a chronic illness. They suggest that all parents have high hopes and dreams for their and their child's futures during pregnancy; this can be crushed when the child is born 'imperfect'. The authors describe the grieving process as similar to bereavement, except that the child is not dead. However, the child they were expecting to have has gone – this is the 'before' child mentioned in paragraph 6.2 of this chapter. Parents have to adjust their hopes and dreams for the child to the 'after' child, the son or daughter who has actually been born. This adjustment is made through adaptation to the reality of life with a child with special needs. Barnett et al (2003) suggest that parents who have not been able to adapt find it hard to respond sensitively to the child's needs.

St John et al (2003) also recognise the significant impact of disappointment and grief on the marital relationship when a child is born with a craniofacial abnormality. The links between this and burn injury can be seen in that the parents need to come to terms with the child's changed appearance, as well as the possible negative reactions of other members of their family and the public.

6.2.1 The impact of burn injury on socialisation

The reaction of others to burn injury scarring is an element discussed extensively by a number of the participants. As well as having to learn to cope with their own feelings on seeing the scarring, the parents also discussed how they coped with public reaction when seeing the child's burn injury. A number of the parents interviewed made reference to the fact that they were concerned that other children or adults might see the scarring and make disparaging comments on the physical effects of the burn injury. In one interview, Mother 1 described what happened on a hot summer's day when her son was playing in the garden with his friends:

Mother 1 'Lewis came in and said could he take his T-shirt off, and it was just an automatic answer from us "No" because we thought they've not seen it, they've not seen his back, ken (know) what I mean and it was like kids'll laugh because of his arm' Page 30 line 27

The parent in this extract explains well her reaction to her son's request to take off his shirt. The use of the word 'automatic' seems to indicate that her concern about exposing the scars was rooted deeply, resulting in an instinctive negative reaction. Both parents were clearly worried that the other children in the neighbourhood would tease their son because of his appearance.

Unfortunately, this concern appears to be based in some reality. Rimmer et al (2007a) questioned a sample of 250 child burn survivors, and found that 61% reported being bullied at school. Significantly more children with visible scars experienced bullying than children with hidden scarring. A quarter of the sample reported bullying to be a big problem for them, but only half of the participants reported the bullying to an adult. The authors recommend that the school, parents

and child should be involved in an anti-bullying curriculum before the child is re-integrated into the school environment.

An extremely concerning finding of the Rimmer et al (2007a) study was that nearly a third of the study sample reported being bullied by an adult. This was a possibility mentioned by one of the parents in this study. In this extract, Mother 8 discusses her concerns about her son's chest and neck scars being visible to others:

Mother 8 'I think its...I'm quite used to it, it's natural to me now cos I'm used to the scarring. I'm frightened of other people looking at it in case people get offended by it and say something wrong to him and he gets a bit upset by it' Page 9 line 11

It is apparent that she is concerned by others expressing revulsion at her son's scarring and making unpleasant comments to him.

For the participants in this study, it is evident that the parents exhibit a desire to protect and defend the child from embarrassment due to their changed appearance. Their awareness of the potential for cruel remarks and bullying from the child's peer group is evident, as is their concern that other adults may make disparaging remarks about the scarring.

However, it is possible that the very natural attempts to defend the child from embarrassment by remaining covered up might have the unintended consequence of preventing the child from learning to cope with being different. By keeping the child covered the parents could be seen as colluding with those who find the appearance of scarring to be unacceptable.

In one interview, Father 3 explains his own feelings:

Father 3 'I think that's what hurts more than anything, the fact that she's going to be marked for life, she can't be a normal kid.....You know yourself, kids are kids. Kids are wanting to rip their tops off and away they go, you know what I mean' Page 7 line 6

He indicates his awareness that his daughter will bear permanent scars, expressing the concern that she can't be a 'normal' child. His illustration of normality for children – being able to pull off clothes and run away to play in the sun - is indicative that he feels that her skin's appearance may cause her to appear unusual. However, the final comment he makes summarises the change that the parents are experiencing.

Father 3 'But we know she is different now. Well, she's not necessarily different but it feels different' Page 7 line 16

This demonstrates the recognition that inside the child is the same, that their essential personality is not different, but that something has changed, because of the instinct to defend the child and prevent exposure, being a parent now 'feels different'.

For a number of the parents interviewed, the concern about others seeing their child's changed appearance had further significance; they seemed to be anxious that the scarring was a demonstration of lack of care. This is shown in an extract from interview 5 where the mother and grandmother discuss with the interviewer the fact that Mother 5 is trying to conceal the scarring on her child's arms:

Grandmother 5 'She also won't let her sleeves be rolled up.

Mother 5 – Don't get me wrong, I can understand why I'm like that, but.....

Interviewer – Do you find that difficult?

Mother 5– I hate it, I hate folks seeing it and asking questions

Grandmother 5 – Heather gets embarrassed.

Interviewer – Do people ask questions?

Mother 5– Yes, and I hate having to say it was because she was burned, do you know what I mean I hate having to say that' Page 15 line 37

This exchange clearly implies that the mother finds the questions prompted by the appearance of the scarring almost shaming. Her repeated use of the word 'hate' suggests that she is still struggling to deal with the sense of guilt she has over the injury.

Another mother echoes these views, although the scarring appears to be less obvious:

Mother 7 'Even now looking at him, I can notice it, most people

cannae(can't) You can just see that this colour is different in his skin, and even that makes me feel guilty. He goes really brown but I'm not going to let him out in the sun without a t-shirt because that's going to burn. That's taken it right down to the next layer. Cos even that makes me feel guilty.' Page 6 line24

The mother in this extract is admitting that the scarring is less obvious to those who are unaware of what has happened. She even alludes to the possibility that sunburn may in the future affect his skin disproportionately, and that this increases her guilt still further.

6.3 Defending the child from victim hood

It is not uncommon to see depictions of sick children in the mass media. Often the media report ill children as ‘courageous, stoical and inspirational’ (Dixon-Woods et al 2003:143). Newspaper descriptions of children affected by cancer will often emphasise the child’s interest in sport or educational attainment before the illness to emphasise the fact that the illness has ‘destroyed’ the child’s normal life and future. Dixon-Woods et al (2003) in an analysis of over three hundred newspaper articles written about children and families affected by cancer also found that life with a life threatening illness was often depicted as a struggle of good against evil with the innocently suffering and heroic child in the middle.

Because of the lay understanding that ‘accidents just happen’, it is also quite usual for burn injured children to be seen as innocent victims of cruel fate (Evans 2001, Girasek 1999). Parents in this study, however, are very clear that this discourse of their child as a ‘victim’ should not affect the rest of their life. They fought to make sure that they kept a positive attitude to the injury:

Mother 9 ‘If we sat back and allowed ourselves to think we were victims of a burns accident then it would just go on for ever. Instead of thinking, this is what we do, this is part of his life. If he’s older and he asks we’ll explain it to him. But unless you make a big issue over it he’s going to carry on regardless, and shrug it off.’ Page 15 line 31

In this extract the parents are demonstrating their strong feelings that allowing the whole family to feel they were victims would have a negative effect. They clearly hope that accepting what had happened and moving on in a positive way meant their son would come to terms with his injury in later life.

Others expressed these feelings in terms of not allowing the injury to limit the child's life:

Mother 1 'We're determined that you'll get better, and we're determined that you'll live with it, that it's never going to hold you back. Mr A {consultant} said we're not going to hold him back from doing anything, he's not to stop riding his bike, he's still to play football, you're not to hold him back from doing this' Page 34 line 8

The impression these statements provide is that the parents are desperate to ensure that the child is able to live a normal life despite the history of burn injury. Their definition of normal life in terms of sporting activities underlines what they feel to be ideal activities for boys to be engaged in.

Another example of professionals encouraging parents to keep a positive attitude to make sure that their child adjusted to life with a burn injury was mentioned by Mother 9:

Mother 9 'One of the nurses in the ward had had a hare lip and she's sort of said you can't allow him to become a victim She said I was bullied when I was about 13 or 14 years old because of the way I looked, and she says to me you just can't. If you have a positive attitude about it then that will carry on in the rest of his life and that's kind of the way we've gone' Page 15 line 34

It was clear that the nurse described in this extract was speaking from her own negative experience of trying to adjust to life with an unusual appearance; however her words reflect that, with a positive attitude, it is possible for burn injured children to be able to go on and live what seems to be a relatively normal life. Showing a positive attitude may also mean that the child is less likely to view themselves as a victim, and will not compare themselves with others who had not experienced the same trauma (Larner 2005).

This hope is based on evidence. Literature around the long-term outcomes in adulthood of burn injured children is in general reasonably optimistic. Blakeney et al (1993b, 1998) conducted two studies of older teenagers and young adults with very severe burns (more than 80% of total body surface area). The authors discovered that the majority of the total sample of 73 participants were adapting satisfactorily without severe psychological or behavioural problems. More recently, Meyer (2004) looked at 101 severely burn injured young adults and found the majority to be progressing satisfactorily in regard to education, occupation and personal relationships. However, the results of the study did indicate that the female participants in the group had more adaptation problems due to concern about disfigurement and unusual appearance.

There is research evidence available which describes the process that trauma patients need to go through in order to adapt to the new reality of disability or changed appearance. Morse (1995) interviewed nineteen adult trauma patients, six of whom had been severely burn injured. From their accounts of their lived experience of recovery she describes a process in which the injured person moves from victim to patient to disabled person. In the first critical stages participants described going through a period of being initially 'engulfed' by their injuries, then 'relinquishing' themselves to caregivers (Morse 1995:889). In the last stage participants described their injury becoming part of their identity and getting to know and trust their altered body image.

Although Morse (1995) carried out the research with a group of adults, it is possible to recognise the links between her findings and that of this study. It was evident that the parents interviewed were very clear in their wish that their child should come to terms with having a different body image, without considering themselves to be handicapped by it.

Parents in this study appear to recognise that there are challenges around living in a culture that puts a high value on physical appearance. One of the parents, whose son had sustained serious burns over his trunk expressed concern about her son's future attractiveness to the opposite sex

Mother 1 – I think about when he meets girls, what are they going to think? I wonder when he gets a girlfriend if she's going to be taken aback. Cos it's not as if he'll go to the disco with his shirt off, so they'll not really see it' Page 35 line 12

This quotation shows her awareness of the fact that physical attractiveness will become important to her son later in his life, but that the fact that the burn was largely hidden except when he had his shirt off could be an issue as the relationship developed and became more intimate.

The awareness of self-consciousness about body image was also mentioned by another mother, whose daughter was injured by a jug of boiling water falling onto her:

Mother 3 'It's not her face or anything like that. She's still marked though, in all the places that she'll see'. Page 21 line 42

Her feelings here are evident – even though her daughter’s scarring is not visible, she will inevitably be aware of being ‘marked’, which may affect her self-esteem and body image in the future.

6.3.1 Self esteem after burn injury

Lawrence et al (2004) examined the relationship between the visibility of scarring from burn injury and self esteem. The authors analysed the results of questionnaires filled in by 361 adult burn survivors with a mean total body surface area burned of 47%, indicating that there was a good representation of severely burned participants. The participants were asked about the burn characteristics including severity, visibility when clothed and whether the participant felt the burn had affected their appearance adversely, as well as questions on perceived stigmatisation, social comfort, interpersonal support and body esteem. The results indicated that burn characteristics were less important than social and emotional variables in determining body esteem. The authors recognised that more research needed to be done to compare the burn survivor group to those who have not been burn injured to find out if social comfort and self-acceptance are more important than physical appearance in assessing body esteem. However, those participants who felt comfortable in interactions with others were more likely to have improved body esteem. This might be used as an argument to improve the social skills of burn injury survivors.

This has been supported by Blakeney et al (2007a), who identify that even patients who appear to others to be functioning satisfactorily on standardised behavioural scales, individual interviews identified that they were experiencing psychiatric symptoms severe enough to warrant diagnosis, especially in relation to social activities. Although physically well enough to participate in normal activities, these symptoms were revealing significant hidden distress and difficulty integrating into society.

Both of the studies mentioned above were undertaken directly with burn injury survivors; an interesting finding of my study was that parents mentioned the visibility of the scarring, particularly on the face, as highly concerning. In particular, Mother 5 was very graphic in her description of her feelings about another child she met whilst on the specialist burns ward:

Mother 5 'One wee girl she'd had skin grafts on her face, she had terrible burns and I thanked God that she's {her own daughter} not got anything like that, they're all on her body. I don't think I could ever have forgiven myself if she'd got it on her face' Page 9 line 27

As explained earlier in this chapter (page 145), the appearance of her child's scars were a constant reminder of her feelings of guilt and shame about the injury, but the sheer obviousness of facial scarring is clearly challenging for the parents as they feel it may attract the attention of others in a negative way.

It seems evident that the parents in this study were anxious about how their child would cope with the reactions of others when looking at their appearance. Mother 1 very vividly described her reactions when others stared at her son's scarring, largely

because it was covered by a mask of clear silicon gel which has a somewhat unusual appearance:

Mother I 'When we went out and he had like plaster on his face, people stared and I thought 'You're ignorant' Then I thought it's maybe us. But it's the way they go about it, I think just ask me about it, don't stand and stare because you'll make him paranoid. You dinnae want to make him paranoid right, and he wears, well at the time he was wearing silicon gel, aye? And he wore like this wee face, and a bit under his chin and you could see folk looking, but Lewis was OK, he thought it was just his gel' Page 25 line 38

This quotation is worth including at length because of the insight it gives into the difference between the feelings of the parent and the burn injured child. The mother here is describing her feelings as they occur – first she seems to feel resentment that people are staring at her child, and then concerned that she might just be being oversensitive. She then moves to the stage of wanting to actually answer the questions about the scarring, rather than her child becoming self-conscious because others are staring. In contrast to her feelings, her son seemed to be taking his appearance very much for granted.

Writings around severe burn injury survivors integrating into society have become more evident in recent years, in particular due to increased survival rates (Acton 2004, Acton et al 2007, Blakeney et al (2007a), Blakeney et al 2007b). In particular, Amy Acton (2004, 2007) has a unique perspective on burn survivorship. Following her recovery from burn injury, she worked as a nurse on a burns unit in the United States and now is the Executive Director of a burn survivor charity. She writes about her recognition that many burn injury patients experience significant long-term psychosocial and adjustment difficulties in the way people respond to them. She

advocates the use of simple strategies to cope with the embarrassment of staring, including projecting confidence when experiencing stares and questions.

The parents in this study discussed their child using this sort of strategy in order to cope with embarrassment. In Interview 9, the parents of a two year old who had been burned by a pot of tea discussed with some humour what they think will be their son's future attitude to his scarring:

Mother 9 'Personality wise, he's got the perfect one; "You want to see a scar? I'll show you a scar" (laughs)

Father 9 'He says to the kids "Will you have a look at that, woah" (laughs) And that's exactly what he'll be like.' Page 16 line 1

Their description of him as having the 'perfect personality' to deal with the reactions of others to his burn injury is an interesting example of how parents may try to anticipate how their child will cope long term with the burn injury. Although the evidence is that in some ways young adults seem to cope quite well long term with adjusting to life with burn injury scarring (Meyer et al 2004, Blakeney et al 1993b, 1998), it can be seen that their reaction to being in social situations with others depended very much on how comfortable they felt with the reactions of others (Lawrence et al 2004).

It could be suggested that the confidence in social situations felt by burn injury survivors has less to do with the appearance or severity of the burn, and more to do with their social skills and personality. Mother and Father 9 quoted in the above extract clearly felt that their son was developing a confident personality despite the fact that he was still only two.

Another set of parents with a six-year-old child at the time of the interview described their son as finding new social situations difficult to deal with:

Father 1 'But he's still like 'You come with me, he won't go on his own or get dropped off. With kid's birthdays at school, he gets hundreds of invitations'

Mother 1 'But he won't go to kids parties'

Father 1 'He won't go because it's strangers'

Interviewer 'Do you think it has affected him, has it taken longer for him to be independent?'

Mother 1 'Aye, it's strange faces that he cannae (can't) get used to, eh?' Page 28 line 44

From this extract it seems evident that their son has found becoming more independent very challenging. They describe him being reluctant to go to places on his own without his parents, and encountering new social situations where there are unfamiliar faces is almost impossible.

This has similarities with a study carried out by Rosenberg et al (2006). The authors questioned ninety-five young adult paediatric burn survivors about their quality of life during the transition between adolescence and adulthood. Analysis of the results identified that the group had a reluctance to engage in new social situations and involve themselves with new people. Despite this, the group appeared to be very satisfied with their friendships. The authors expressed surprise at this finding, but it could be possible that although finding new friendships was difficult, once they were established young people found them to be helpful.

Despite the realisation of parents that children found new situations to be challenging, they did express strong views that the child had to learn to cope in the environment where they were burned, rather than avoiding it entirely. In this

environment the child would have to learn to deal with danger, even if this involves exposure to burn risk. Mother 1 described how she and her husband coped with their son returning to the kitchen where he had been very badly burned by a saucepan of boiling water:

Mother 1 'And he doesn't run around in the kitchen, he was right wary, kind of watching, but I thought dinnae no take him there because you don't want him to have a fear of going back' Page 31 line 13

Having moved into the final stage of adaptation, where the parents are trying to ensure that their child returns to as normal a life as possible, there is evidently a realisation that it is important that the child is able to return to a kitchen. From the description, however, although he has been able to return, he still seems to be wary of the kitchen as a potentially hazardous environment.

The desire that the child should not be frightened of the environment where the injury occurred is also evident in other accounts:

Mother 8 – He still comes in the kitchen, he still wants his Pot Noodles. It hasn't traumatised him' Page 8 line 47

Although much briefer, this mother evidently feels that her son needed to return to the place where he was burned. She also clarifies the means of the burn injury.

6.4 Conclusion

This chapter has developed the theme of ‘defending’ by analysing two elements. The first is that the parents wanted to protect their children from feeling ashamed of their changed appearance. In order to do this, the participants discussed how they themselves learned to come to terms with their feelings about their child’s scarring, as well as how they struggled with protecting the child from the negative remarks of others.

The second is how the parents attempted to deal with the fact that their child might be regarded as different to other children, a burns ‘victim’ who could be expected to find it difficult to integrate into normal society because of their different appearance. This perception of their child as different, unable to adapt to the normal friendships and social networks of the normal child’s world, was something that clearly concerned them a great deal. They express determination that they will try to help their child to lead a normal, active life as far as possible, and as far as they can to help them to come to terms with their feelings of fear about the place where the injury occurred.

Having presented a suggested model for parental adjustment to burn injury in the preceding three chapters, I now aim to address the other part of the research aim and present an analysis of the participant’s description of their experiences of healthcare, in particular during their child’s admission to an acute paediatric ward.

CHAPTER 7

‘LIKE SOLID GOLD’: PARENTAL EXPECTATIONS OF ACUTE PAEDIATRIC AND COMMUNITY HEALTH PROFESSIONALS FOLLOWING BURN INJURY

7.1 Introduction

The preceding three chapters have introduced and presented a model of parental adjustment to burn injury. However, the experience of parenting a burn injured child is, especially in the initial stages, lived within the context of acute healthcare settings. For parents of a critically ill child, life on a hospital ward resembles ‘being in an alien world’ (Hall 2005:179), where parents need support and direction from health professionals to help them to make sense of this new and strange environment. Parents understood that although the new world was strange to them, for the professional staff it was familiar territory, and they looked towards both the nursing and medical staff to meet their family’s healthcare needs.

Although some of the parents had previous experience of their child being admitted to hospital, for the majority, treatment following the burn injury was the first time they encountered acute paediatric care. Without exception, the parents described the experience to be difficult and stressful, and the clarity of their memories seemed to underline the impression that their time in the hospital had made on the whole family.

It was clear from the interview data that the behaviour of the professional staff encountered by the parents during their first experiences of parenting a burn injured

child was critical in helping them to adapt and cope. Although previous research has highlighted the skills required of paediatric nurses by parents (Miceli and Clark 2005, Cescutti-Butler and Galvin 2003, Noyes 1998, Callery and Luker 1996, Darbyshire 1994), the data reveal that parents in this study appeared to have very specific and particular expectations of nursing staff which have not necessarily been identified before in this context.

Through analysis of the parent's description of their relationships with health professionals, I identified that parents expected nursing staff in particular to:

- Care for the child as a person
- Demonstrate a high level of skill
- Meet the needs of the child, the parent and the family
- Provide absolution for the parents for their feelings of guilt and being responsible for the injury
- Allow parents to act as partners in the care of the child

In this chapter, each of the themes is identified from analysis of the data, and considered in relation to the wider literature available.

7.2 Caring for the child as a person

For the majority of the parents interviewed, the burn or scald injury resulted in their first experience of their child being a hospital patient. For a number of participants this resulted in a significant challenge to their views of themselves as parents. This

element has been discussed in detail in earlier chapters of this thesis. However, the experience also meant that the parents needed to adjust their view of the child from living only within the family setting, to becoming a 'patient', existing within the context of the hospital and the primary healthcare system.

Shields et al (2003b) recognises this shift of awareness experienced by parents, and suggests that the perception may be best explained as a concept of ownership. In the view of these authors of a preliminary discussion paper, the question of ownership of the child has a profound effect on the relationship between parent and professional in a hospital setting. They recognise that the term ownership has negative connotations, but argue that it might have influences on the parent perception of the power relationship between nurse and parent. Although there has been discussion in earlier chapters on the views of parents on power and control in their relationship with professional staff, it is clear that the participants in this study recognised that the staff on the ward had assumed responsibility for the care of their child, as well as responsibility for the care of many others.

This sharing of responsibility, or in the words of Shields et al (2003b:213), shared 'ownership' between parent and professional was challenging for some parents interviewed, as they were clearly aware that although unique and special to them, their son or daughter was just another injured child in a busy ward:

Mother 3 "I mean when you think about what's actually going in and out of that ward the whole time." Page 11 line 8

The parents of burn injured children are likely to be resident or visiting the ward for a relatively long period of time in contrast to the short admissions of other trauma

and plastic surgery patients. This gave the parents appreciation of how busy an acute paediatric ward could be. However, despite the hectic environment, during the interviews participants expressed a strong desire that their child should be treated as a precious individual during their hospitalisation, and needed some demonstration from professionals that their child was seen as special, not just as another patient or in some instances as an extension of the parents.

This mother of one very young child described in detail how nurses valued the child as an individual, apparently making the effort to interact directly with the child as a distinct personality, rather than using the parents to speak for the child:

Mother 9 'It wasn't just about how you deal with parents it was how you also deal with the child. He was only nine months old, couldn't walk, couldn't talk, couldn't anything but they treated him as an individual not just as our kid, or we'll do everything through the parents.' Page 9 line 23

For this parent, there seemed to be awareness that staff appreciated both child and parents were important members of a family unit. The extract also demonstrates a realisation that the professionals were making an effort to get to know the child and to assess his personal needs. Parental appreciation of this is greater because of the age of the child – even though he was unable to articulate his needs the nurses made a real effort to understand the child rather than simply expecting the parents to interpret the needs and wishes of the child.

Those parents who gained the impression that nursing staff were genuinely interested in their child as an individual seemed to find it easier to form a rapport with staff, enabling them to trust and respect the staff member, and therefore the care that the

child was receiving. Espezel and Canam (2003) also identified the importance of treating the child as an individual for developing a rapport with family parents in their study of parent interaction with nurses. This qualitative study of eight parents of seven children with chronic health conditions seen in ambulatory clinics in a large urban children's hospital, identified that parents felt the degree of rapport was greatly influenced by the nurse's knowledge of the child as an individual as well as a patient. Establishing rapport between the nurse and parent was essential to allowing shared and individualised care.

In contrast to this, Kristensson-Hallstrom and Nilstun (1997) tell of situations where the staff failed to take the child's views and opinions seriously. This resulted in the child and the parents failing to feel acknowledged and respected as individuals. In their study of twenty parents with a child admitted to a paediatric surgery department at a hospital in Sweden, they describe situations where nurses minimised the pain that children were feeling and therefore failed to provide adequate analgesia. They also reported the parental view that nurses assumed children only complained of pain from clumsy procedures when the parents actually objected. The parents that they interviewed saw this as violations of their rights and the rights of their child, with staff failing to treat the child as having views and opinions about their own care.

Valuing and becoming involved with a small number of patients and their families has been recognised as a way of improving care by nursing staff in particular. The introduction of primary and named nursing has been an attempt to increase patient

satisfaction with their care (Sellick et al 1983). In the next section, I discuss participant awareness of this policy.

7.2.1 The role of the named nurse

The ability of nurses to get to know the child and the parent in hospital settings appears to be influenced by the implementation of the widespread and well-established practice of assigning a named or primary nurse to each patient (Dooley 1999, Steven 1999). It was noticeable that a number of the parents interviewed mentioned that their child was allocated a nurse, or had a named nurse, and parents were extremely positive about this:

Mother 3 'It's like Chloe got personal attention by one person all day. It was like she wasn't getting chopped and changed you know.' Page 11 line 38

Mother 1 'Hannah she was on for the first few days he was there, and he kind of got used to seeing her face'. Page 127 line 9

The mothers here clearly felt that by having a 'known' or named nurse that the child could recognise gave their child a measure of comfort and familiarity in what was an alien setting. This allocation of staff meant that the child received 'personal attention' from a professional, allowing the parents to feel that their child was special to someone in the ward environment and more likely to get the care they needed in a sensitive manner.

In some instances, the nurse seemed to provide 'extra' attention to their child, showing additional care and commitment to the child and the family. This element

of 'going the extra mile' is mentioned as an important element in the work of Calman (2004) where patients appreciated nurses doing things for them that were not necessarily part of 'nursing care' as such, but meeting the needs of the patient as an individual. One of the interviewees in the Calman (2004:172) study mentions a nurse giving him a photo frame for a photograph of a friend who had just died, as well as physically being there to provide care and comfort following his bereavement. This was plainly important to him as it demonstrated an understanding of the patient as a human being with a life outside the hospital.

Gift giving was also mentioned by one of the mothers interviewed for this study. Mother 5 expressed great pleasure that her daughter's named nurse gave her daughter a gift as a reward:

Mother 5 'Her mum {the nurse's} had been at the bingo and she'd won a big teddy, a rabbit and she brought it in and gave it to Rachel for being a brave girl'. Page 9 line 1

This gift was clearly very important to the mother on two counts, it demonstrated to her that the nurse was willing to 'go the extra mile' in caring for the child, thinking of her outside the workplace and demonstrating an involvement with the family that was more than superficial.

However, for this mother, the soft toy was not just a casual gift; it was a reward for her daughter's behaviour – given because she had been a 'brave girl'. The mother here felt this confirmed that the nurse was giving approval and praise to the child for being a 'good' patient, a factor that was clearly important to the mother.

Mother 9 also considered her child to be treated as special because of his 'good' behaviour whilst on the ward.

Mother 9: 'I'll always remember, they came round in the morning and they were standing waving at him outside the room. They were so taken with him I think because he was really well behaved; he was smiley and things like that.' Page 8 line 6

The parents descriptions of their observations of how their children's good behaviour resulted in positive acknowledgement by nurses is an interesting extension of the concept of patients feeling compelled to behave in a particular way in order to be deserving of nursing attention. Although, there is little written regarding the child as a 'difficult' patient, there has been fairly extensive literature published regarding the 'difficult' adult patient (Calman 2004, MacDonald 2003, Steinmetz and Tabenkin 2001, Johnson 1995). In these studies, the difficult patient is usually one defined as ungrateful, aggressive, and uncooperative. However, there is little published literature on what patients are expected to do in order to earn status as a 'good patient'. In particular, it is noticeable that in one particular study, Johnson (1995), patients were given an informal label of 'difficult' or 'deserving' patient not necessarily because of their medical condition but because of their efforts to 'get on' with the staff by being helpful and friendly. In my study it is the parents who felt their children were the perfect patients because they were 'smiley' and 'well-behaved'.

As well as appreciating the positive consequences that having a named nurse had on the child, parents also felt that having a specific nurse allocated to the child, gave the family valuable support too:

Mother 9 'But certainly the nurses become very involved with you.

There were a couple of particular ones through the night that would sit and chat which was an enormous support. 'Cos once John {husband} left, you just feel well, "I'm on my own, I'm out of my depth"'. Page 12 line 2

The participant's views on the nurses' role to support parents will be explored in greater detail later in this chapter, but it was evident that the parents felt that it was important to have a small number of staff members that became familiar with the family. A number of the parents describe a feeling of 'being alone', 'out of depth' and insecure following the admission of their child to hospital as a result of an injury. For example, Mother 3 refused to stay in the ward without her partner as she felt insecure:

Mother 3 'I couldn't stay over at night-time 'cos they did give me a parent's room, but Scott (partner) couldn't get there. I'm very insecure on my own, so I said I'm just going home with Scott there and I'll come back in the morning. I couldn't stay over' Page 11 line 25

It appears that for this parent, even having familiar nurses there was insufficient to make her feel confident enough to stay in the ward, although she later praises the nurses for giving her support and caring for her as an individual.

Analysis of the data from this study proved to be revealing regarding the value of the named nurse. Although parents were aware of the fact that their child had been admitted to a very busy ward, with a number of patients requiring care, participants clearly appreciated nursing staff who appeared to get to know their child as an individual. The named nurse approach clearly helps the family to build up a good rapport with the nurses, and this is crucial in enabling the parents to entrust them with the care that their children needed to receive. An interesting extension of this

role was that some of the parents interviewed believed that their child received extra approval and attention because of the good, brave behaviour that they exhibited, because this was valued by the named nurse.

As well as demanding that nursing staff should be involved and interested in their child, participants also revealed that they had certain expectations of the skills that nursing staff would demonstrate. The next section provides an examination of these expectations.

7.3 Nurses demonstrating a high level of skill

The parents interviewed for this study revealed that, on admission, they assumed and expected that nursing staff would be highly skilled in the care of their child, not only to treat the injury and preserve life, but also to minimise the pain and stress of treatment for the child and family.

Mother 1 gives a vivid account of this expectation when she first arrived at the specialist unit after transfer from the district general hospital:

Mother 1 'When I got to {specialist children's hospital} I thought, thank God, there's nurses, ken (know) what I mean, I thought all these people ken what they're doing' Page 11 line 37

It is unclear on what basis the mother decided that the nurses in the unit 'knew what they were doing' in the specialist unit compared with the district hospital, but it

seems likely that her opinion was based on the swift way that the nursing team were able to get the child monitored and comfortable.

Mother 1 ‘....and before I knew it he was hooked up on machines and sleeping in my arms’ Page 11 Line 32

The ability of parents to judge the technical quality of care for their children in the child’s hospital stay appears remarkable, as none of the parents interviewed had acute paediatric medical or nursing experience. However, the parents had gained, through very close observation of the care of their child and others on the ward, a large body of knowledge of the ‘correct’ procedures. A noteworthy example of this was the account one set of parents gave of having to instruct a student nurse who was failing to follow what they had observed to be the correct procedure for giving medication through a naso-gastric tube:

Father 3 – ‘I was trying to say to her, I don’t think you’d better do that, and she’s sort of saying “Eh?” And I said “You’re meant to do it with a wee bit of water, I’ve been watching what you’ve been doing” and she was like “Aye, but she telled me to plunge it through” and I said “You need to do it with a bit of water, not a whole bloody syringe of air” so that was it’ Page 11 line 7

This extract illustrates well initial reluctance on the part of the parents to tell the nursing staff what they should be doing. At the beginning the father is merely hinting that the nurse is not using the correct technique; as it became clearer that she really did not know what procedure to follow he became more graphic in his description of what she should be doing.

Callery and Luker (1996:346) describe in detail a mother’s recognition of when her child’s intravenous infusion was blocked, even without nursing or medical

knowledge. They considered that it was surprising that parents developed the ability to judge the technical quality of their child's care even during relatively short hospitalisations. Yet, in their account of the blocked infusion, the mother was able to give detailed descriptions of what the doctor should have been doing, again suggesting close observation of the care given to the child, supporting the findings of this study that many parents were able to judge technical quality of care based on close observation of different staff over different periods of time.

It seems likely that parents were able to judge the competence of the staff because of the relatively long time that some of the children remained in the ward. This meant that parents had the opportunity to watch a number of different staff members carry out the same procedure. This was particularly noticeable in the account of Mother 1, who gave contrasting accounts of the quality of technical care by different members of staff when undertaking dressing changes. She first gives an account of a skilful dressing change; her description merits quoting at length because of the poetic, flowing quality of her words:

Mother 1 'They kind of had it all planned, like this is what's new, and what's going on. All the bandages waiting, and they had the creams and that on them and this is what's coming off, and they had the wee tray there, and it was a matter of right, cut off the bandages, get the swabs, everything was prepared and let's get the next ones on, and that's it. Minimum time, right, and I'm like OK, and we done it really well.'
Page 16 line 5.

Shortly following this, she gives an account of a dressing change where the nurses appeared less skilled. The mother had been present during the previous four or five bandage changes so had been able to form an opinion on what she considered to be the 'correct' procedure.

Mother 1 'And there was one at a weekend.....and I was going nuts. I thought' 'What are you doing?''and they were just swanning about, and they weren't organised. They started cutting him, cutting his bandages off without even having anything, and I thought wait a minute, I've done 4 or 5, normally everybody's quite set in their way, Page 16 line 15.

This account gives a clear outline of the mother's growing awareness that these nurses were perhaps less experienced, and certainly less prepared for the dressing change. Her experience of seeing four or five dressing changes had convinced her of the correct process, the realisation that the nurses in this case were not preparing to do the procedure correctly increased her anxiety that her child would experience unnecessary pain and distress.

In this study, some of the parents seemed to retain very clear feelings of anger regarding clumsy care given by inexperienced staff. This is perhaps a measure of the stress parents feel observing that their child could potentially suffer because of some shortcoming in their care. Other authors also report this as a significant stressor, in particular Darbyshire (1994), who gives several accounts of parents with very clear memories of shortcomings in nursing and medical care given on paediatric wards.

It is clear that parents managed to gain a good knowledge of what they considered to be the correct care for their child, largely due to close observation of the procedures carried out by professionals with their children. It seems that parents demanded that staff possessed a high level of technical skill mainly to reduce the possibility of the child having to endure further pain and suffering, and parents plainly felt that they had a duty to intervene if they felt unskilled care was evident.

As well as demanding skilled care for their child, parents also revealed that they had expectations that professional staff would meet their own psychological and personal needs. The next two sections are concerned with an analysis of the parents' narrative on their expressed needs, and the extent to which professional staff were able to meet these.

7.4 Meeting the needs of the child, the parent and the family

It was evident from the parents interviewed for this study that their child's hospitalisation had a great effect on the wider family, as well as on the child and the parent staying with them on the ward. This evidence contributes to an increasing recognition that although the child is the patient, the whole family is greatly affected by the admission of the child to hospital (Shields et al 2003a, Bialoskurski et al 2002, Shields 2001, Callery 1997a, Callery 1997b).

Their child's admission to hospital had significant practical effects on the parents interviewed for this study. Parents described the need to make arrangements for their other children and their homes while they were at the side of their child on the hospital ward:

Mother 2 'He (partner) was supporting the rest of the kids, doing the jobs, he kept the house clean so it wasn't bad, he didn't let it go to rack and ruin. My friend and my sister, they were quite supportive. My friend came down to baby-sit, brought her two kids as well, things like that'. Page 9 line 30

*Interviewer 'So how about your other children because you've got older children as well? Who looked after them?'
Mother 8 - Well it was family, quite a lot of family' Page 7 line 25*

Participants described needing to depend on family members to care for their children and make sure that their practical arrangements at home continued. As well as these social costs, there were also financial costs incurred by the families. Mother 9 described the measures she had to make to ensure she was able to eat whilst on the ward with her son:

*Mother 9 '.....in {specialist children's hospital} the cafeteria/restaurant is down three floors, outside the hospital away round a couple of buildings then up another flight of stairs.
Father 9 'It's appalling'
Mother 9 'And then you get there and there is nothing worth eating so at that point you went to Marks and Spencer's and got a whole load of ready meals for me so I used to go down to the parents unit that they had, microwave it and then bring it back downstairs' Page 7 line 34*

It was evident that for this family, the sheer complexity of accessing the cafeteria drove them to make their own arrangements, with their associated costs.

Other parents interviewed also described spending considerable amounts of time travelling from home to the specialist hospital to be with the child, the difficulties of finding parking, and the challenge of having to negotiate time away from the workplace. All these elements had to be carefully managed for all the families. For the parents included in the study sample who were struggling with health or social issues the help of supportive staff appeared to be even more vital.

Other writers have recognised the financial, social and personal cost to parents of their child's admission to hospital. Callery (1997a) interviewed the parents of twenty-four children who had been recently discharged from a surgical ward at a

large teaching hospital in England. He found that in general it was the child's mother who stayed with their child in hospital; those who were in full or part time employment lost either income or holiday in order to be present. During their child's hospital stay they had to pay for their own food at the hospital, which could be expensive. They were also supplementing the food and drink provided for their child, which added to the financial burden. Using a literature review to assess the effects of hospitalisation on children and parents in both the developed and developing world, Shields (2001) also recommends that the parent's need for support and help in managing the practicalities of the child's admission should be met by professional staff.

For some of the parents in the study, because of mental or physical health difficulties, it was evident that their need for support was greater than might normally have been expected. Mother 3 experienced a very high level of anxiety due to a longstanding history of mental ill health. In addition to this, she had fairly recently become pregnant for the second time, which added to her anxiety:

Mother 3 'It was like I thought, I'm 22 weeks pregnant, I do not want this, anything happening. I need to calm down' Page 3 line 47

She felt very strongly that nurses were caring for her because she was pregnant, as well as for her injured daughter:

Mother 3 'Aye, but Mel and Clare, and all that, they were brilliant, they kept constantly coming in to find out how I was, cos with me being pregnant as well you know, they were saying you've got to eat. "Come on, get yourself down to the canteen and get something to eat"'. Page11 line13

These encounters had clearly made a great impression on this mother, who had encountered serious difficulties in coming to terms with her child's injury.

Another mother also described nurses encouraging her to look after herself for the sake of her child:

Mother 7 'They were just there if I wanted a break. 'Cos I didn't want to leave him and they kept saying "Go to the house and get a cup of tea, we'll watch him. You need to be OK as well, you need to be fit for him, not just sit there and have no tea or anything".' Page 5 line 19

This data illustrates parents showing awareness that they felt they were being cared for as much as the child; that they had become, in the words of Callery (1997b), a co-client. The data illustrate how the nurses express concern that the mothers are meeting their own needs, in order to be able to meet the needs of their children. During the interviews, these parents expressed a need to be cared for and the participants clearly felt that the nurses were providing a measure of care and support for both them and their child. For these parents, it could be identified that they had definitely become co-clients with their child, and therefore the object of care and support from the nursing staff (Callery 1997b).

However, for some families where only one parent was resident, and the other parent had to care for the rest of the family at home, it was evident that for that parent, not being present on the ward meant that they risked not having their support needs met. One father interviewed felt so much focus was placed on caring for the mother, that he was ignored:

Father 9 'I found it particularly difficult, I think, I don't know if I've ever said this, but the focus is very much on the mother, I found it bloody tough because I was having to cope with him in hospital, having to cope with you staying in hospital, I was having to cope with the house, with Peter {older brother}, the school, our friends but everybody thinks of the mother and that's not your fault, that's not anybody else's fault but I don't think anybody gave a second thought to what I was going through except for you{mother}, nobody else did.' Page 12 line 8

This quote is interesting and revealing, as it emphasises that for many families there was still the need for life to continue outside the hospital. Parents often had other children that needed to be cared for; the normal life of work, caring for a home and interacting with other family members still needed to continue outside the artificial world of the hospital ward. The father here clearly identified the need for someone to provide help and support to allow normal family life to continue outside the hospital as far as possible. According to some of the available literature on this subject, it could be suggested that this is a suitable role for the health visitor to fulfill (Marsh et al 1995). However, none of the participants recalled contact being made by their health visitor whilst their child was in the hospital. This may have been a reflection of the ambivalence felt by health visitors when considering post-injury interventions (Combes 1991, Reynolds 1996).

In summary, many of the parents, particularly those who were resident in the hospital, were very positive about the care that they felt they received from the professionals, in particular the nurses. One parent described the nurses as being '*like solid gold*', (Mother 1 page 15 line 33) and this view was echoed by most participants. However, it was evident for those who were not resident that it was a great deal more difficult to get the help and support that was clearly needed.

As well as needing the practical help and assistance during their child's admission to hospital, participants also discussed their need of psychological support at what was clearly a very stressful time. A number of the parents interviewed mentioned guilt and shame at allowing the injury to occur as their overriding emotions.

7.5 Providing absolution for the parents about their feelings of guilt and being responsible for the injury

Guilt for allowing the injury to occur is, as already discussed, a common thread running through the data. For many parents interviewed, guilt is mentioned as the dominant feeling experienced by them immediately following the injury; it is evident from the data that the response of healthcare staff to this feeling is significant for the relationship parents build with professionals.

Guilt experienced by the parents of children in hospital has been mentioned by a number of writers. Hopia et al (2005) describe parents as having a 'bad conscience' during their child's hospitalisation, and Darbyshire (1994) has also found that parents tended to blame themselves directly for their child's injury, assuming that by 'allowing' the accident to happen they have failed in their duty to protect the child. He described that parents expressed awareness that nursing staff formed judgements on their parenting and this had a strong influence on the parent's moral standing in the ward.

However, although data from this study reveals that parents realised that they were under scrutiny, and therefore felt strong pressure to prove themselves, they also looked for nurses to help them to mitigate their strong feelings of guilt, to assuage their conscience. They almost seemed to seek explicit absolution, and felt upset if this wasn't forthcoming.

One parent at interview recounted amelioration of her guilt by staff as almost her first comment on nursing staff:

Mother 5 'The ones at {specialist children's hospital} reassured me, made me feel it wasn't my fault, it was an accident.' Page 4 line 22

This was in direct contrast to the experience of Mother 6, who expressed a need for nursing staff to give more comfort to ameliorate her guilt. In contrast, she felt staff considered that as the adult she had failed in her duty as a parent:

*Mother 6 'I just felt they were pretty condescending, quite 'Well, OK, your child's been hurt but you're the adult here' and...
Interviewer 'How did that make you feel?'
Mother 6 'It makes me feel quite bad actually 'cos it was an accident, accidents do happen and unfortunately, you know, it did' Page 7 line 38*

Parents had a high level of contact with nursing staff during their child's admission, so in general it was this relationship parents tended to comment upon. However, some of the participants mentioned interactions with medical staff as having great significance, especially in relation to their need for reassurance and forgiveness. In some cases, the parent/professional relationship seemed to depend upon the professional telling the parents they were not at fault for the injury occurring. This

was very evident in the interview with Mother 2. Following admission to the hospital, there was some suspicion that the burn injury might have been non-accidental, and the parents underwent a number of interviews with medical staff. This caused significant trauma, but the mother commented on the fact that the nurses were consistently supportive, and were making the effort to care for her as well:

Mother 2 'The nurses were lovely, the doctors were terrible' Page 3 line 30

Later in the same interview, she comments on the nurses making judgements on whether the injury had been deliberately caused by observing the reaction of the child with the parent. The nursing staff were clearly very aware the parents were finding being under suspicion to be traumatic, but child protection procedures demanded that reassurance could not be given until investigations had been completed.

Mother 2 'One of the nurses actually says that she knew we didn't do it cos she says that they have more experience with children coming in, and the way Ryan reacted with us, they knew that we hadn't been bad to him, but she said that we were really worried, and everything was going to be fine, but they couldn't tell us that.' Page 4 line 5.

In this case, the mother needed more than reassurance that the injury had not been her fault, the suggestion that she might have deliberately caused the burn injury caused enormous distress during the twenty-four hours that she felt she had been under suspicion. The detailed recounting of this conversation demonstrates how important it was to the mother; she needed to hear that the nurses had observed the child behaving normally, seeing this as conclusive evidence that staff no longer thought that his parents had 'been bad to him'. This conversation provided the mother with the confidence to know that at least the nurses accepted that the burn

was not deliberate, even though the mother still felt guilt that she had ‘allowed’ the injury to occur. However, the mother clearly felt that the doctor who had initially suspected the injury was non-accidental should have apologised once they considered the injury to be unintentional, but this did not happen, and it was evident that this was still affecting the mother’s memory of her experience:

Mother 2 ‘You know what I mean, if they’d came and apologised I would have been totally happy, but because he didn’t acknowledge the fact that he had tormented us, even though it was only 24 hours, it was 24 hours too long’ Page 15 line 6

This element of needing professional forgiveness when an injury has occurred is important for how health professionals and parents engage in any discussion of the injury event and its consequences. It is apparent from the findings that parents do not want nursing or medical staff to add to their feelings of guilt by blaming them for the injury. However, some participants clearly wanted healthcare professionals to tell them it wasn’t their fault, and that ‘accidents happen’. Without this reassurance, parents clearly felt short changed. However, as I explored in Chapter 6, there may be a mismatch between the parents wishing to believe that ‘accidents happen’; a chance occurrence that could not reasonably have been avoided (Girasek 1999) and the professional view that referring to an accident is a false construction implying injury cannot be prevented (Evans 2001, Bijur 1995). The evidence from this study is that parents look for professional reassurance that they are not blamed for the accident; despite their feelings of compassion towards the parents, professionals may find it impossible to move away from their belief that injury is preventable.

Once the initial shock of the injury had faded, and the parents had started to come to terms with their feeling of guilt, it was evident that participating in care was important for a number of different reasons.

7.6 Allowing parents to act as competent partners in the care of the child

Parents interviewed expressed varied attitudes to becoming involved in the care of their child. The majority expected to participate in care, at least in the day-to-day practical care of the child on the ward:

Mother 4 'Well, it's not a holiday, and it's not a break! 'Cos you're there really as their primary carer' Page 6 line 9.

This mother expressed how she differentiated between the technical nursing of her child, and the caring for her child. She explained how she still expected to fill the practical mothering role, and felt that was the reason why she was present in the hospital. She clearly assumes that although the hospital had taken on the technical, medical part of her child's care, the day-to-day care of the child remained in her hands.

Some parents were happier to be involved in the more technical parts of hospital care than others. Mother 3 found it impossible even to look at her daughter without the bandages:

Mother 3 'Cos they knew, I couldn't even go and look at her, they were saying "Chloe's going in for a bath, are you wanting to go and have a look?" and I'm like "No, Scott, I can't, you go in and see, and then you can tell me."' Page 11 line 16

For this mother, the sight of her daughter's burns was apparently too much to cope with. She clearly wants to know how they are healing, as she asks her partner to go in and see how they are, but is unable to witness the bath herself.

In direct contrast to this was the annoyance expressed by Mother 1 when nursing staff suggested that she leave the room during a dressing change:

Mother 1 'They sort of like said 'Excuse us' and I thought ' No, I wait here', and I was quite taken aback and I says I've always been with him with his bandage changes, and I'm going to watch this one' Page 16 line 21

Here the mother seemed to be seeking a role for herself as able to contribute to the professional care of her child. She had already expressed some reservations about the standard of care provided by the nurses in this situation; her desire to stay with him was partly driven by the need to ensure the dressing was done properly, but also wanting to be a direct part of his care. What this mother seemed to be seeking with all the staff caring for her child was a 'collaborative relationship' (Espezel and Canam 2003:38). The authors describe this type of relationship as characterised by professionals being open in giving information about their care of the child, attempting to establish rapport with the parents by accepting the importance of the parent's views and opinions and showing technical competence. The mother here felt that this relationship did not exist with these nurses, so refusal to leave the room reflected her concern.

Piira et al (2005), in their literature review on parental presence during medical procedures, suggest that parents who perceive their presence to be helpful provided

them with an important sense of control. One situation in which parental presence was not permitted was whilst the child was in theatre and this was mentioned as a difficult time by a number of parents:

Mother1 'See if they'd have let me, I would have been in there with my gown on.

Interviewer - Would you have been happier signing the consent form if you had been able to go in?

Mother - Oh, aye. If they'd said, can you sign that and then you can come in I'd have signed it and been standing waiting for them'. Page 18 line 19

This mother explained that she was concerned about the anaesthetic, mainly due to the well-publicised recent case of a local child dying whilst under dental anaesthesia. Being forced to separate from the child intensified this mother's concern for the loss of her child in theatre and heightened her anxiety.

Risk of anaesthesia was an issue mentioned by another mother interviewed. She vividly describes the moment when her son was 'put to sleep':

Mother 2 'He was meant to get put to sleep by the injection and I was quite upset by that, but they decided to put him to sleep by gas and it was horrific. They took him down to theatre and he sat on John's knee, and to see fear because obviously he didn't know what was happening and he had this rigid body with this look of fear on his face, he just slumped and slept'. Page 5 line 28'

Although parents found watching the induction of anaesthetics to be challenging, the policy to allow them to be present is now well established and recognised to have benefits for both child and parents (Romino et al 2005, Kain et al 2003, Kain et al 2004, Blesch and Fisher 1996, Cameron et al 1996). However, these authors do accept that it can be a strange and stressful environment for parents, and good support is essential.

Participation in care has become a central element in what has become defined as 'family centred care'. However, although as both Coyne (1996) and Shields et al (2006) assert in analytical reviews of the development of family centred care in the United Kingdom, it is questionable whether there is actually a single definition of 'family centred care'. In particular, Coyne (1996:2) suggests that it can be 'conceptualised as a composite of attributes relating to the family, nurse and their relationships'. These attributes include the negotiation of care between professional and parent, so will inevitably be affected by the willingness of professionals to cede power, control and autonomy to parents, as well as the perceived competence and willingness of the parents to take on the responsibility for participating fully in their child's care. The introduction of a sense of guilt into this composition could, I suggest, add an interesting extra dimension into the concept of parental participation.

As discussed earlier, many parents expressed guilt at the occurrence of their child's injury. In order to ameliorate this guilt some parents expressed a desire to be involved in their child's care to mitigate their guilt for allowing the accident to happen. This approach to reducing feelings of guilt has been identified in other research. Hopia et al (2005) identified that parents try to compensate for their guilt at the child's hospitalisation by giving their own labour whilst on the ward, arguing that parents believe attention from nurses needs to be earned through their participation in the care of the child.

This effort to deserve approval from professionals is also mentioned by Darbyshire (1994), who believes that parents feel obligated to show they were competent to care

for their child by their willingness to cooperate and become involved in care on the ward. This is reinforced by the data in this study. The determination of Mother and Father 1 to ensure that the outcome for their son is as good as possible is very clear in the following extract:

Father1 'I think partly like the blame side of it as well, we felt with being responsible for it, it made us extra careful about making sure it got better.

Mother1 - It's like, you ARE going to get better, we'll make sure.

Father1- We'll make sure' Page 34 line 1

The resolve of these parents to compensate for any shortcomings they feel they displayed for 'allowing' the injury to occur resulted in them trying to manage the aftercare well. They appeared to have entered the category of 'expert parent' (Darbyshire 1994) where their opinion was sought by professionals regarding other patients:

Mother 1 'They've even been asking us what kind of creams we would advise other parents to use, because she said she had another kid coming in who had grafts on his back and it was like thick leather, and his mum was getting all frustrated' Page 34 line 32

Another set of parents also described taking the responsibility for the child's recovery:

Father 3 'At the end of the day, she's going to be scarred for the rest of her life.

Mother 2 - Aye, but depending on how good we are with the moisturiser, the pressure garments, and that'll limit that.' Page 6 line 47

The mother here clearly felt that being given clear tasks that they could do to help their daughter's recovery was something very positive. For this set of parents, who were struggling with the reality of their child's injury, participation in care was seen

as an essential coping strategy, an element also noted by Evans (1994) who interviewed parents who were taught how to administer intravenous antibiotics to their children. She found that the parents felt their practical involvement gave them something positive to focus on which increased their confidence and made them feel they were doing something to 'fight for their child' (Evans 1994:479).

Unfortunately, not all parents felt that they were being treated as competent partners in the care of their child. The interview data revealed occasions when parents definitely felt that the attitude of some professional staff discouraged their involvement in the care of their child. The mother in the following extract was clearly very angry at what she saw as the poor attitude of one of the surgeons when he stayed outside the child's room and discussed the child's care without involving the mother:

Mother 7 'And it was my mother who said they were out talking outside..... I looked out, but he never ever came in, the surgeon, he never come into the room, he just stood outside.....But that frustrated and annoyed me cos the surgeon that was treating him should come in and speak rather than stand outside the entrance. You know they're speaking but you can't hear them, they're standing outside the room'
Page 4 line 42

The feelings of exclusion and annoyance are clear in this quotation – not only did the surgeon appear to exclude the mother from the conversation about her child, but by standing outside the door while talking, the impression that was given was one of information being shared that the family was not party to. The very real anger that this provoked was expressed in another extract from the interview:

Mother 7 'And then a surgeon who we'd hardly even met to stand outside the door and who hadn't even looked at his burn, cos the other surgeon was on his days off, just standing outside and talking and just walking away without speaking to me'. Page 4 line 12

The mother appeared to feel that her views and opinions as the parent were being ignored. In her opinion, the health professional/parent relationship had moved away from the ideal of the collaborative relationship (Espezel and Canam 2003) where the consultant seemed to make no effort to establish a rapport with the mother, or communicate clearly.

In this study, parents seemed quite clear about what they expected as far as partnership in care was concerned. The amount of involvement in the technical elements of care varied according to how comfortable the parent felt about seeing the child's injury at close quarters, but all the participants seemed happy to be involved in the practical, day-to-day caring tasks that they would have carried out in the home. What many of the parents sought was a collaborative relationship with the professional staff, where their rights, views and opinions were validated and they felt that their role as parents was recognised.

7.7 Conclusion

In this chapter I have introduced and discussed the themes identified from the interview data in relation to the parent's views and opinions of their experience of healthcare, in particular during their child's admission to the hospital ward.

It could be seen from my interpretation of the data that parents had very definite expectations of professional staff, but also clearly discussed specific needs that I identified as unique to the parents of burn injured children in particular.

Despite the fact that their child was being nursed on a hectic acute paediatric ward, parents needed evidence that their child was as unique and special to the staff as they were to their family. During their interviews, the parents discussed specific incidences when they felt that the nurses provided this evidence, especially when they showed appreciation of the child as part of a family unit. It was evident that the policy of providing a 'named nurse' for each child on the ward helped parents to build up a supportive relationship with a particular staff member. Parents also demonstrated awareness of how their child and their own behaviour on the ward affected their relationships with professionals.

Parents revealed themselves to have clear expectations of the skill that the nursing staff should demonstrate in the care of their child. They very quickly gained an understanding of the correct techniques that should be used, and were able to give detailed and descriptive accounts of when skill was demonstrated, and conversely when it was not.

As hospital staff were the first professionals to come into contact with the family immediately following the burn injury, parents also looked to them for reassurance and forgiveness that the accident could not have been avoided. As a result of the strong feelings of guilt expressed by all the parents interviewed, the attitude of staff

in their attribution of blame for the injury became of significant importance to the participants.

These strong feelings of guilt contributed to the overall traumatic experience of having to witness their child undergoing painful and distressing treatment. Parents expressed their need for personal help and support, whether this was practical help on coping with the impact of hospitalisation on the whole family, or being given comfort and care themselves.

Finally, parents expressed a very clear need to be treated as competent partners in the care of their child. As well as being able to grasp the skills needed to care for their child, parents wanted to use their own labour to ‘make up’ for allowing the injury to occur.

In the next chapter, I will present how the themes in the preceding four chapters can be linked together to demonstrate how health professionals can aid parents to adapt to their role as parents of a burn injured child.

CHAPTER 8

‘I’M ON MY OWN, I’M OUT OF MY DEPTH’

SUPPORTING PARENTS THROUGH ADAPTATION – THE ROLE OF HEALTHCARE PROFESSIONALS

8.1 Introduction

The previous chapters have described the themes associated with the adaptation of parents to their child’s burn injury. It has been demonstrated that family adaptation can be considered to be a process, and the analysis of parental feelings and actions helps to identify and describe each of the stages of this process. Chapter 7 contains the views and opinions of the participants on the care that they and their child experienced both while they were being cared for in the acute paediatric setting, and after discharge.

The stated aim of this research study is to examine the impact of childhood burn injury on the family, whilst gaining an understanding of the healthcare experience of parents. The aim of this next chapter is therefore to examine how the ideas explored during the analysis of the participants’ views on their adaptation to the reality of parenting a child with serious burn injury link with the themes identified around healthcare and professional intervention. In this chapter I develop knowledge on how professionals can more effectively help and support the parents of burn injured children to successfully adapt to changes in their family life and parenting.

8.2 Helping parents to ‘be there’

As I described in the detailed analysis in Chapter 4, the parents interviewed for this study described an overwhelming urge to hold and be close to the child. This stage had two elements: the first an instinctive need to comfort and help the child, which was labelled ‘instinctive holding’; the second was the parent’s desire to be identified as the most important human being in that child’s life, an element described as ‘intentional holding’.

Within Chapter 7, I explored two themes, ‘providing comfort and care for the child and the parent’ and ‘allowing parents to act as partners in the care of the child’. In interpretation of the views and opinions of parents which allowed the development of these themes, it was evident that parents were looking for professional staff to meet their own needs including their need to stay close to the child, but also to consider how the care of their child could be carried out in the context of an established family unit. Bearing this in mind I discussed how professional staff helped participants in this study to maintain physical closeness with their child. However, the parents in my study expressed the desire to increase the amount of time that they spent with their child, particularly during times of extreme stress for example after theatre. In order to explore this, I have labelled this linked theme ‘helping parents to be there’

8.2.1 Parental presence during burn injury treatment

There is longstanding evidence that allowing parents to be present and participate in the care of their children can help to reduce stress for both the child and their parents, and make a significant contribution to successful outcomes (Piira et al 2005, Alsop-Shields and Mohay 2001, Simons et al 2001, Shields 2001, Kristensson-Hallstrom 1999, Coyne 1996, Darbyshire 1994).

Analysis of the interview data from this study indicates that those parents who were able to stay with their child also felt a much greater sense of control, and seemed to sense that having their child removed from them would distress both the child and themselves in a stressful situation.

Evidence for the benefits of parental presence has been provided by a systematic review of research on the presence of parents during medical procedures (Piira et al 2005). The authors attempted to increase the robustness of the review by only including those studies where each group of children with parents present were matched with a concurrent control group with parents absent. A total of twenty-eight studies were selected, looking at children and parents in a variety of age groups, and during a wide range of medical interventions including immunisation, venepuncture, and induction of anaesthesia. The conclusions from the review indicated that the evidence about the effect of parental presence on child behaviour during medical interventions was mixed, with some studies reporting children fared better, some where they fared worse, and others where there was no difference. However, the positive effect on the parents was much more evident, with parents either reporting they felt much better than those not present, or that there was no significant

difference. The authors suggest that although their presence did not influence child distress, the parents derived benefits from being with their child. According to Piira et al (2005) the parents felt that they were able to help their child positively and gain a real sense of control, whether or not the child was showing distress. It could be suggested that having a sense of control also made parents much more able to feel they could cope with their child's distress.

For the majority of the participants, their descriptions of holding their children indicate that professional staff accepted the need for the parent and child dyad to be kept together. However, there were clearly times when the parents felt that this closeness was threatened by the staff working with their child. As mentioned in the chapter on holding, participants mentioned their concern at being asked to leave their child during treatment, but also their feelings around the time that their child was undergoing surgery. Several described their feelings of loss of control when the child was taken away into surgery; one parent described that she would have felt much more comfortable if she could have been in the theatre with her child.

A number of the participants mentioned being present while their child was given the anaesthetic, and the benefits of this policy are now well recognised for both child and parent. In particular, a number of researchers have identified that being present reduces manifestations of stress in parents and children (Kain et al 2003, Kain et al 2004, Blesch and Fisher 1996, Romino et al 2005, Cameron et al 1996). Some of the parents described this as being a difficult time for them; they had worries about the safety of anaesthesia and found watching their child being 'put to sleep' very

stressful. However, all felt that being able to hold and be with their child was valuable for them.

With regard to the time immediately following surgery, however, it is evident that there is very little available research literature about the impact of parental presence. This is reflected in the views of the participants, where there was significantly little mention of parents being present with the child immediately post-operatively. The one exception is found in data from one interview. In Chapter 4 I present an analysis of the feelings and opinions of Mother 1 and Father 1 about their child's physical reactions to waking up from the anaesthetic. In this case, the parents were called into the recovery area due to the distress of the child; it was not routine for the parents to be there. Data from this study suggests this is a stage where holding their child might help calm the child, and also help parents to feel a greater sense of control. Smith and Bassett (1996) are two of few researchers who have looked at the introduction of parents to the post-operative recovery area of theatre. In reporting on a practice development project encouraging parents to be present in recovery, they noted that the trial was considered to be overwhelmingly positive for staff, parents and children. The parents interviewed felt that the practice helped to allay anxiety; they felt part of the process and therefore more in control and it was helpful for the child as they were able to be physically closer. The quotes provided by the authors frequently express the concept of 'being there' as most important to the child, whether or not the parents felt they were actively included in providing care for the child. The staff questioned also felt that it had positive benefits for the child in that parents were able to tell if a child was in pain, and also could act as an advocate for the child.

Another study (Hall et al 1995) questioned parents and recovery area staff following a similar change in practice at a specialist children's teaching hospital in a large English city. The authors also found that both staff and parents felt that introducing the practice was beneficial, with nearly all of the parents questioned expressing the view that being present in recovery was helpful to their child. These are both helpful, if small-scale studies and it is regrettable that there seems to have been little research on this subject in the last decade to build on these results, particularly in the United Kingdom.

More recently, Kain et al (2007) reported a study carried out in an American hospital with a policy allowing parental presence in the recovery room. The results indicated that parents who had been given an education programme prior to their child's admission to hospital were more easily able to calm their child during their time in the recovery room. This suggests that in order for parental presence to be useful, some preparation is essential.

However, some authors have identified that although both staff and parents express the realisation that being allowed to participate during treatment will help both child and parent to cope better, in fact this concept has been applied ineffectively in many settings. For example, Simons et al (2001) used a phenomenological approach to interview both parents and nurses about their perceptions of parental involvement in pain management. The definition of involvement mentioned in the study was for nurses to give written and verbal information on the drugs and equipment used for pain management and to encourage parents to identify when their child was in pain. Both groups identified an understanding that involvement was in many cases merely

passive – the parents were present with the child and had an understanding of the treatment that the child was receiving but did not actually have direct involvement in providing pain control.

They also recognised that the parent being with the child had two functions: the first was to recognise when the child was distressed due to pain, and to seek intervention with pharmacological pain relief, and the second was to help provide non-pharmacological pain management with distraction techniques and comforting the child through physical contact. This suggests recognition that parents have a vital part to play in helping staff to understand their child, and also to provide complementary care to the medical intervention provided by the professional staff.

During the interviews, the participants in this study describe their overwhelming and instinctive need to hold their child, recognising that having the parent/child dyad physically close together had benefits in providing comfort to both child and parent. Being physically close to the child seemed to help to calm the child, especially during potentially painful treatment, and this had clear benefits for health professionals. However, it also allowed the parent to feel that they could have some more control over the situation. Those times when the parent was separated from the child, most often whilst the child was in surgery, were clearly challenging for the parents, but the evidence seems to be available to suggest that allowing parents to be present in the recovery area after surgery has benefits to both parts of the parent/child dyad.

8.2.2 Being involved in decision making on care.

The other element of holding, ‘intentional holding’, has been analysed in detail in Chapter 4. However, it is possible for strong links to be drawn between this theme and another of the themes revealed in the analysis of the parent’s views about their healthcare experience. In Chapter 7 I discussed the wish of parents to be recognised as competent partners in the care of the child. This was partly to allow parents to cope with their guilt at their perceived responsibility for the injury, but also to allow them to regain some power. This has clear links with the theme of holding in order to be recognised as the most important person in the child’s life – therefore intentional holding required that the parents were involved in the child’s care by being allowed to be present during treatments, as well as feeling involved in the future of their child’s care. There was also a feeling that parents wanted to be informed at every stage of the child’s progress.

Parents felt that being involved in the care of their child was important to meet their need to be seen as pre-eminent in their child’s life. This seemed to help parents to cope with their feelings of guilt and responsibility for the injury and help them to regain their lost feelings of competence. The interview data revealed that participants considered the professional role is to ensure that the parents are allowed to be involved in the child’s care, if they wanted to, but also to be involved in decision making about the care of the child. As the hospital environment is challenging for both child and parent, especially in terms of the difficulties of parenting under the scrutiny of others, it seems particularly important for the

professionals to allow the parents to be identified as the most important person in the child's life.

However, in some situations this parental expectation may be unmet, in particular in situations where non-accidental injury is suspected. Although in this study cases involving proven non-accidental burn injury were specifically excluded from the sample criteria, a number of parents did recall quite detailed questioning around the circumstances of the injury. Professional dissatisfaction with the responses to questioning may lead to parents being excluded from decision making in care and even prevented from being with their child while criminal enquiries are carried out (Sanders and Cobley 2005).

8.3 Helping parents to be 'in charge'

My analysis of the interview data revealed that following the injury parents felt an imperative to 'guard' their child. This manifested itself in a strong feeling that it was their responsibility to keep their child away from danger. In Chapter 5 of this thesis, entitled 'We wrapped him in cotton wool', I further explored the development of this 'guarding' theme. It was further divided into three sub-themes: guarding from injury, guarding from the environment and guarding the child from the world.

The first sub-theme, 'guarding from injury', was recognized when the parents described their attempts to keep the child physically away from perceived danger. The second, 'guarding from the environment', was identified when parents disclosed feelings of overwhelming responsibility to ensure that their child was in a safe

environment, and reveal how their experiences have affected their views of danger. The third sub-theme, 'guarding the child from the world', was a development of the second. Following the injury, many of the participants expressed views that children in general are vulnerable, special and need extra protection from an increasingly dangerous world.

In the chapter on the development of the guarding theme I suggested parents felt that protecting their child from danger was not only the 'job' of the parent, but also a moral imperative. Therefore, by allowing injury to occur, it may be that parents feel that they have failed both in their job to keep their child safe, but also in their moral duty as a parent. Parents speak of the challenges of 'parenting in public' (Darbyshire 1994), and their feelings of guilt and shame at allowing their child to become injured. My chapter on healthcare themes proposed that parents looked to health professionals to provide absolution for the parents in their feelings of guilt and responsibility for the injury. It also suggests that they try to compensate for their guilt during the child's hospitalisation by giving their own labour whilst on the ward in order to 'be worthy' of attention from nursing staff or demonstrate competence in parenting (Hopia et al 2005, Darbyshire 1994).

8.3.1 Regaining confidence and coping with guilt

The role of professional staff in helping parents to regain confidence in their parenting abilities after their child is injured is also vital. Analysis of the data suggests that parents look to professional staff for absolution in their feelings of guilt

and responsibility for the injury. This can be a challenging aspect of supporting parents at this time as often professionals are involved in questioning parents about the circumstances around the injury (Scheidt et al 2000, Combes 1991). There was understanding among the participants that there would need to be some questioning about the circumstances surrounding the injury, and the parents indicated their understanding that this questioning acted as a necessary safeguard for children. However, once this initial stage had passed, parents clearly expressed very specific needs, which included professional staff telling them that they are not to blame for the injury.

I also proposed that parents needed to be allowed to be partners in the care of the child (Chapter 7), particularly in the stage immediately after discharge from hospital. I identified this as a time when the parents considered that they were largely responsible for ensuring that the on-going treatment of the burn injury was as good as possible. I have already suggested that for parents this may be a way of regaining their feelings of control that they may have lost especially while the child was in hospital. However, by allowing parents to be partners in care, it could be seen that professionals are allowing the parents to regain some of their feeling of competence in their 'job' as a parent. Therefore, they have not only regained moral authority as parents by being told that the injury was an accident, and couldn't have been prevented, but also that they are considered by professionals to be capable and competent enough to assume the main responsibility for the aftercare of their child.

This concept of professionals providing moral validation for the parent whilst on the hospital ward has been studied extensively by Darbyshire (1994). He found that parents whose child had been injured in an accident seemed to feel more obliged to re-establish their identities as good parents. He suggests that parents strive to do this on the ward by being present with their child, and found that parents sensed strong disapproval from professional staff when they left the ward.

8.3.2 'Being there' to guard the child

Developing this theory, then, it could be suggested that these feelings of needing to be near the child whilst in hospital is a manifestation of the instinct to guard the child – parents feel that publicly 'being there' for the child is a way of guarding the child, hovering over them. It was certainly evident that some parents felt a reluctance to leave their child, with one mother in particular describing her actions as just spending her time pushing her child up and down the ward in a pram, until the nursing staff managed to persuade her to leave the ward to have some food. She describes having to build up trust in the staff to leave her child, but this also implies that the parents themselves need to feel that they have sufficiently convinced professionals that they have regained the moral authority as protectors of their child by hovering over them to protect them.

Darbyshire (1994) describes this as establishing a moral purpose, with parents feeling that they needed to be with their child to show their 'goodness' both to professionals and to other parents. However, the parents interviewed for the study

reported in this thesis revealed more than this; they seemed to feel that only by being physically able to guard their child both in the hospital and when at home will their moral authority as protectors of their children be re-established.

Darbyshire (1994) noted that parents with burn injury felt more of a pressure to re-establish their identity as competent parents whilst on the ward because of their guilt that their child had become injured whilst in their care within the home. Analysis of the participants for this study also indicates that this is an issue for parents, once the child has left hospital; parents are then faced with the task of mothering or fathering their child with a new understanding of vulnerability, and a new imperative to protect the child. Many had to learn to cope with the guilt of their child becoming injured. The compulsion to guard the child continues when the child is discharged from the hospital environment. Therefore, the need for validation, education and support from professionals remains as parents continue in the process of adaptation at home.

8.3.3 Parental validation through family surveillance

It is possible that mothers and fathers may look to professionals to give validation that they are capable of doing a good job as a parent, but also to be reassured that they cannot be condemned as 'morally inadequate' as parents for permitting the injury to occur. This validation can only be achieved by the parent accepting the role of health professionals in family surveillance, with the associated implications of disciplinary power.

The power of health professionals, in particular child health professionals, to exert disciplinary power by carrying out surveillance has been well examined by a number of authors (Normandale 2001, Wilson 2001, Peckover 2002, de la Cuesta 1994, Dingwall and Robinson 1993, Armstrong 1993). It seems evident from these writings that this disciplinary power involves making judgements on the ability of parents to adequately care for their child. Two studies have, in particular, examined parental views on the role of health visitors in judging and assessing parenting effectiveness. Machen (1996) interviewed twenty first time mothers to discover their opinions on the health visitor service offered to them. She found that all the women were extremely positive about the health visitor role, with a perception that the service offered was to provide support to the mother as well as to care for the well-being of the mother and baby. Only a quarter of the participants mentioned the health visitor role in 'policing' the family, and those that did seemed to perceive this as an unacceptable stereotype that was largely broken down by the relationship built up with their own health visitor.

Peckover (2002) interviewed a group of mothers (n=16) who were experiencing domestic abuse, and their health visitors. Her analysis of the data revealed that both groups felt that although health visiting work is concerned with the health and well-being of women, its primary concern is with mothering, and the women's ability to care for her child. She uses a quotation from a mother who readily admitted that she always 'put on a good face' to 'kid the health visitor' (Peckover 2002:373) and conceal the fact that she was experiencing domestic abuse by projecting herself as organised and cheerful. Other mothers in the study described how they deliberately

avoided contact with the health visitor because they were threatened by their authority, which some perceived to be inspired by a middle class ideal of mothering. These descriptions highlight the tensions between the health visitor's role in supporting the parent, and their standing as an authority figure representing the disciplinary power of the state. Peckover (2002) describes the women interviewed as demonstrating the ambiguity between needing the support and help of a knowledgeable professional, and resenting the scrutiny of mothering that this relationship implies.

It is noted by a number of authors that this scrutiny is frequently carried out in a covert manner. In a critical analysis of the surveillance carried out by child health nurses (known as 'Plunket' nurses) in New Zealand, Wilson (2001) suggests that although the care given to families is intended to sit firmly within a partnership model of care, in fact discussions with five nurses reveals that they depend on the home visit to reveal knowledge about the family that might not be voluntarily revealed by the mother in a clinic setting. Wilson (2001:298) goes on to propose that the parent/nurse relationship is established and maintained by professional efforts to form a 'wonderful relationship' with the mother. Drawing on Foucauldian ideas she suggests that professionals manage their clients in the guise of an equal relationship by masking power relations and avoiding overt coercion. However, interviews with the nurses reveal that they are aware of the concept of resistance to surveillance, with all five participants revealing doubts over the total honesty of the parent/nurse relationship. She suggests that the mother is reluctant to jeopardise the relationship by telling the nurse that she has not followed advice.

Foster and Mayall (1990), following interviews with health visitors and mothers, also describe professionals working in a covert way during home visits ‘surreptitiously’ (page 288) using the basis of their good relationship with the parent to introduce health education messages. Dingwall and Robinson (1993) also suggest that home visits may be used to further health education or assessment covertly.

Both of these studies seem to represent mothers’ views as perceiving the surveillance or policing role as a negative one. However my analysis of the data for this study revealed that in contrast to this, parents not only readily recognised this role of surveillance, but also actively looked for it when needing validation of their ability to parent. They felt that having a professional able to provide a judgement on their competence was helpful rather than threatening when questioned in respect of an injury to their child.

It has previously been discussed in Chapter 6 that participants are aware both of the surveillance and supportive role of health visiting in regard to keeping their children safe. Participants in this burn injury study also discuss an ongoing relationship with their health visitor as important, but for the majority of parents interviewed, the potential supportive role of the health visitor appeared to be more important than the surveillance and judgement role. Machen (1996), in a qualitative study of twenty mothers, also reported that parents felt health visitors should ‘be there’ for them. She found that although the mothers interviewed were aware that for many the health visitor might appear to have a policing role, personally the large majority of those

interviewed felt empowered rather than judged by health visitors. For them, the relationship was facilitative, rather than controlling or directive.

The supportive role of the health visitor links well into the sub-theme ‘guarding from the environment’. As has been noted in my study, parents talk at length about having learnt through the injury to their child that children need to be protected from a dangerous world. They deal with this awareness by trying to ensure that they maintain a safe environment for their child both in and out of the home.

8.3.4 Professional support to maintain a safe environment

However, there was understanding among the parents in my study that there are difficulties in keeping their child safe especially when there are many distractions associated with child rearing. Roberts et al (1995) also noted that parents perceive inherent difficulties in incorporating safety practices into everyday life. The parents interviewed in my burn injury study acknowledged that their child’s injury made them more aware of the danger in the environment, but expressed the view that other factors get in the way of ensuring that there is always a safe environment for the child.

During this guarding stage of adaptation, it was evident that the parents in my study were experiencing greatly increased anxiety about maintaining a safe environment for their child. They indicated the desire for professional intervention to offer support for them in making their home safe, as well as in supporting and facilitating them to

cope with feelings of guilt and distress following their experiences. It was apparent that the parents felt they had changed their behaviour significantly as a result of the injury, and felt that this was putting a strain on their daily lives. For example, some of the parents interviewed described at great length the efforts they went through to ensure that their children were safe in their home. Two of the interviews contained almost obsessively detailed accounts of home routines reflecting a very real concern that despite their best efforts, their children might be unsafe. This stage was clearly extremely stressful for the parents interviewed, and for a number it was apparent that professional support would have been helpful.

In contrast to this expressed need, it was noticeable that there seemed to be very little involvement from the primary healthcare team after the injury had occurred. Some of the participants mentioned some contact with health visitors, but this seemed to be informal rather than as part of a package of support.

Parents did mention briefly the role of their health visitor in safety education; some mentioned they attended safety information sessions in the antenatal period, or had been provided with written information. However, despite specific questioning by the interviewer, no parents mentioned having been visited by their health visitor after the injury had occurred. Some parents were offered support, but did not take up the option; others would have appreciated more support from their health visitor.

8.4 Helping parents to 'defend' - defending

In Chapter 6, I discuss my identification of the final stage of parental adaptation to burn injury as 'defending'. This theme has two elements. The first, defending the child and family from shame, is concerned with the parents wishing to help their children and themselves to come to terms with the reaction of the world outside the family to the physical effects of burn injury scarring. The second part of the chapter is subtitled 'defending the child from victim hood'. It contains an interpretation of the parent's discussion on their feelings about their child's future and how they would manage to integrate and be part of society when they may feel socially uncomfortable because of their unusual appearance. The participants discuss their strong feelings that their child should not be a 'victim', with all the negative connotations of this concept.

These themes, then, can be linked with two identified in the analysis of parents' views and opinions on their healthcare experience: meeting the needs of the child, the parent and the family, and allowing parents to act as partners in the care of the child.

It was clear from the parental accounts that professional staff spent a significant amount of time supporting them to cope with the appearance of their child's burn injuries. In the ward setting, this was often an issue during treatment, for example at bandage changes, and it was evident from a number of accounts that although parents were given the opportunity to see their child's exposed burn, some were unable to

actually be physically present at these times (see chapter 7 page 179). The data also revealed that in some families, although one of the parents was often present during ward based treatment, the other parent would elect not to be present.

In order to demonstrate comfort and care to the child and the parents, and also to allow involvement in care, it was important that staff found some way of facilitating the parents to see and come to terms with the appearance of their child's burn.

8.4.1 The use of photography to support parental adjustment

If the primary caregiver was not present during treatments, it was apparent that staff were faced with the need to use some sort of visual information to inform the parents about the likely appearance and progress of burn injury, and it was evident that photography was used very extensively during the treatment period. From the data it appeared there were two methods of using photography to work with the parents of burn injured children. The first method was to inform the parents of how specific treatments, for example skin grafts, would look post-operatively. In this case, generic photographs were employed which demonstrated the different types of surgical treatment. Generic photographs were also used to demonstrate to the parents that children who had had similar burn injury treatment to their child had experienced good wound healing.

The second method used by professional staff was to take actual photographs of the child. These were used to inform the medical team of the progress of the burn in

between dressing changes, but were also used to show parents how far the burns had progressed with healing. The use of photography was particularly evident for parents who were not actively involved in the care of their child's burn injury; either they were not physically able to be present at dressing changes due to other commitments, or they felt psychologically unable to see their child's injury.

The use of photographs in this way appeared to be a valuable aid to care for and support parents, and I would suggest that this means of support is possibly under appreciated in research literature on the use of photography to prepare parents for difficult procedures.

There is good evidence available regarding the use of photography as a means of enhancing the care and treatment of the burn patient, especially more recently due to the advent of digital photography. Nelson et al (2006) assessed the usefulness of routine digital photography of all burn injury patients admitted to a large specialist burns unit in Scotland. Using a questionnaire, the authors asked professionals working in the unit to evaluate the extent to which photography was used as an aid to assessment, education, management and patient care. Although seventy four percent of the respondents (n=43) agreed that photography was helpful to improve patient care, the main advantages were seen as reducing bandage changes, assessing wound healing and moving and handling. No mention of the use of photographs to inform and support patient and family recovery was mentioned at all.

The use of digital photography to enhance communications between members of the burn care team was also assessed by Van et al (2004). Following the introduction of a new communication tool combining the use of digital photographs with text instructions on the use of positioning and splints in the treatment of burn injury patients, nursing staff were asked to complete a questionnaire on whether the new tool was helpful in ensuring that the correct techniques were used with every patient. Of the twenty two questionnaires that were used in the final statistical analysis, all the respondents felt that the use of digital images combined with text was more effective than using text or photography alone. The study was not intended to assess the feelings of patients, and did not involve them in any way.

Studies assessing the use of photography in child burn injury are limited, however Johansen et al (2004) carried out a feasibility study on the use of email communication with a specialist burns team in Norway. Four families were recruited to take part in the trial, and were asked to send weekly digital photographs of their child's burn injury to the specialist burn team. The main aim of the research was to assess whether the quality of the pictures taken by the parents was sufficiently high to be used for clinical decision making on treatment. However, the parents were also asked to give feedback on their experience of using the method. It was significant that the parents felt that it helped them to be more involved in their child's progress, and assisted them in understanding and appreciating that their child was doing well. It was also assessed to be helpful in that it avoided having to travel to the hospital, something that was seen as reducing stress on both the child and the family. Clearly this was a very small feasibility study, but it does demonstrate the use of

photography is seen as helpful in supporting parents to monitor the progress of healing, especially if they live a long distance from a specialist unit.

An account of how photography was used to encourage coping in family members was given by Angermeier (1991). In the example he discusses, the burn injured patient was a mother with an eight year old daughter, who was severely burned in a road traffic accident resulting in extensive and destructive burns to the face and scalp. In order to prepare the child for her mother's changed appearance a series of photographs was used, and explanations of the images were given to the child. The use of these photographs appeared to have aided the child's adjustment to her first sight of her mother, and resulted in her appearing to be comfortable with the disfigurements.

Although there does not seem to have been a similar detailed study of the use of photographs in the preparation of parents for seeing their child's burn injury, it was evident from the accounts of the parents involved in this study that this method was often used for those parents who struggled to look at their child's changed appearance, reflecting their grief at the loss of their 'perfect child' (see Chapter 6 page 140). Looking at photographs, particularly retrospectively, as a means of seeing how far a child's healing had progressed, was clearly less challenging than the struggle to look at the injury on their own child as treatment was carried out. It is therefore important that staff assess the ability of parents to cope with seeing their child's scarring, and use the most appropriate method of supporting parents to manage their feelings about their child's altered appearance. It was clear, however,

that all the parents benefited from seeing generic 'before and after' photographs of burn injury, which allowed them to gain a better understanding of what they could expect in the future.

8.4.2 The information needs of parents

As well as the issue around scarring, parents are faced with the difficulty of coming to terms with the change from having a healthy child to one experiencing ongoing medical intervention. In their interviews, analysed in Chapter 5, parents expressed their need for information which would allow them to feel confident about caring for their child on discharge from hospital. It seems likely that information that increases confidence will in turn increase family resilience.

This was confirmed by a finding of Rolland and Walsh (2006) who write that families are more likely to cope with the challenge of illness within the family unit if professionals are able to give them some guidance on the expected practical and emotional demands that are likely to occur. The authors also suggest that professionals should provide the emotional support to help parents pull together as a family unit, and information to cope with the developmental changes in their child that can occur during the course of the illness or treatment.

In their outline of an intervention to promote parental adaptation to the condition of a child with special needs, Barnett et al (2003) describe adaptation to grief at the 'loss' of the perfect child that the parents were expecting, as a normal process that all

parents must go through in order to resolve the negative feelings that they may experience. The authors found that parents were more likely to adapt to their child's condition if it involved a correctable condition, such as cleft lip and palate, which could be resolved surgically rather than a motor impairment where the child will not walk. They claim that in that case the parents may only experience a grief reaction when the child is unable to do things that a normal child would at that age. They advocate a group intervention which would help parents understand the ongoing challenges, and develop the confidence to cope in the future as their child changes and develops. Bearing this in mind it seems likely that the parents of burn injured children will need to have support in coping with their child's movement into adulthood.

In Chapter 6, which discussed the final stage of parental adaptation which I labelled as 'defending', I presented at length an analysis of the words of the parents in regard to how they wanted to ensure that their child was able to move into the adult world without being seen as a victim, and allowing them to adapt successfully in a world where appearance is seen as important.

Although a number of parents were clearly aware that the child's burn injury would have long term implications, if, as Barnett et al (2003) claim it is possible that parents may have a delayed grief reaction to their child's injury, professionals have the task of preparing the family for the developmental issues that will occur in later life. For example, boys with facial and neck burns will be faced with issues around shaving and uneven beard growth (Lawrence et al 2004). Adolescent girls with burns

to the arms and trunk may find wearing the same revealing clothes as their friends to be difficult (Meyer 2004). Burn scarring on the breasts and abdomen may have implications for women during pregnancy and breastfeeding (Polko and McMahon 1998). As specialist professional staff may have appreciation of these issues, they are in a unique position to support parents as they face them. As I have already demonstrated, parents feel very strongly concerned that their child's burn injury may affect their self-esteem and social competence as they move into adolescence and adult life.

8.4.3 Interventions to support families affected by burn injury

Burn injury professionals also recognise self-esteem as an important element in psychological and psychosocial adjustment, and have designed a number of interventions to support burn injured children and their families. The use of support groups for children and adolescents with chronic medical conditions is well established (Funck-Brentano et al 2005, Carter et al 2004, Mitchell et al 2007), and their use in supporting burn injured adolescents has been evaluated by Chedekel and Tolia (2001). The authors undertook a questionnaire survey of twenty young people between the ages of 11 and 20 who were attending a weekly burns support group at a specialist burns unit in the United States. The results indicated that the vast majority of the respondents would continue to attend the group and would recommend it to others. The expressed benefits of the group to the attendees were the opportunity to network and share experiences with other young people in the same situation. The

participants also welcomed the opportunity to learn from each other and express their feelings on how they had adapted to life as a burn survivor.

Particularly in the United States, other structured interventions to support burn injured children and their families have been based around attendance at burn camp. Supported by professionals, and on occasions staffed by burn injury survivors (Cox et al 2004), the burn camp provides a unique opportunity for children with burn injury to socialise and learn from others who have had similar experiences (Rimmer et al 2007b, Arnoldo et al 2006, Cox et al 2004, Piazza-Waggoner et al 2004, Adams et al 2002). There has been a large amount of interest in the effect of attending burn camp on the long term self-esteem of child burn survivors, and although research reporting self-esteem measures demonstrate mixed results, the camps have been found to be beneficial for many young burn injury survivors. One detailed study of children attending such a camp in the United States reported that they found it to be a socially supportive environment, where they felt that their body image was accepted because they were with others who also had scarring (Cox et al 2004). There were also positive effects reported from being supported to undertake new and challenging activities.

In the United Kingdom, rehabilitation support for families of burn injured children has generally been provided by a partnership between the statutory and voluntary sectors. Burn care professionals working in the National Health Service are usually involved in providing professional advice and support, but the cost of the camps and other events are usually covered by fundraising and charitable donation. The

contribution that these camps provide for rehabilitation has been recognised by the National Burn Care Review (National Burn Care Review Committee 2001).

8.5 Conclusion

In this chapter I have linked the process of parental adaptation with the themes identified when the participants discussed their experiences of healthcare. These links have allowed a discussion on how professionals can help to support parents who are adapting to living with a burn injured child.

The first part of the chapter, 'Helping parents to be there', contains my argument on how health professionals can support parents to be physically close to their child, with a recognition that this helps to reduce distress in both child and parent. Allowing parents to participate in care also helps them to regain the feelings of power that they may have lost when the child was injured.

In the second part of the chapter, 'Helping parents to be in charge', I link together the defending stage of adaptation with the expressed need for professional forgiveness and support to regain feelings of parental competence. I present a discussion on the expressed parental need for support from health visitors to maintain a safe environment for their child, but also suggest that parents welcome the surveillance and policing role of health visitors if it provides validation of their parenting.

In the third part of the chapter, 'Helping parents to defend', I present discussion on how healthcare professionals can help parents to come to terms with their feeling

about their child's scarring and the 'loss' of their perfect child. In particular there is discussion on how those parents who found it extremely difficult to look at their child's burn injury during treatment can be supported to follow the treatment, and be informed of the likely outcome of the burn. There is also an examination on the role of professionals in supporting families to adapt when their child moves through the developmental stages of adolescence and into adulthood.

In the final chapter of this thesis I will present a summary of the findings, recommendations for further research and suggestions for improved practice.

CHAPTER 9

SUMMARY AND RECOMMENDATIONS

9.1 Introduction

The research study which has been reported in this thesis was designed with the aim of building an understanding and appreciation of the long term impact of childhood burn injury on the family. By examining the narratives of parents during the treatment of their child, and understanding how these experiences have affected parenting, conclusions can be drawn on how health professionals might most effectively support the family living with a burn injured child.

The following chapter contains a summary of the key findings of the research, discussion on the implications of the findings on current professional practice, and recommendations for further research on this subject.

9.2 Background to the study

The study reported in this thesis originated from discussions with parents and professionals encountered during my coordination of a local childhood injury prevention project. It became evident from speaking to individuals who had either professional or personal experience that burn injury had great impact both on the child and the family. By studying childhood burn injury in detail, it was anticipated

lessons could be learned that would raise awareness of the long-term effect of burn injury and improve the support to families offered by healthcare professionals.

A detailed examination on the effects of burn injury reveals that there can be long-term physical and psychological impact of this type of injury on children, especially as they move out of childhood and into adolescence. There are also significant effects on family functioning. It is agreed that a stable, supportive family environment is essential to promote good recovery (Barnum et al 1998, Rossman and Gamble 1997, Blakeney et al 1990), but as some evidence points to young people with burn injury experiencing significant difficulties in adjusting as they grow older (Meyer et al 1994), it could be suggested that parents need to develop high levels of responsiveness and sensitivity as they support their children to recover.

However, it was apparent from research that having a stable, supportive family environment may not be the experience of many children who are burn injured. The evidence is that families living in poor quality, overcrowded homes on a low income are at higher risk of burn injury (Delgado et al 2002, O'Connor et al 2000, Alwash and McCarthy 1988). This is coupled with research suggesting that parents living in deprived socio-economic circumstances or pre-occupied with mental health problems or substance misuse issues are less likely to engage in effective safety practices (Hapgood et al 2000, Kendall-Grove et al 1998). Therefore, it seems evident that high risk of burn injury is strongly associated with exactly those factors which are likely to make the family less resilient and successful at adjusting to the impact of the burn injury.

Previous research, therefore, suggests that the support and help of professionals is essential in order to help the family through the child's recovery from burn injury. The aim of the project was to discover if this support was effective for one particular group of parents but also to understand the process of adjustment, in order to inform health professionals on how they can offer effective support at all stages of adaptation.

9.3 Conduct of the study

From an area in the central belt of Scotland, a group of nine families with children who had been burn injured while less than five years of age were recruited. In order to ensure that each participant had significant experience of the phenomenon to be examined, the study criteria included only the parents of children who had been treated in the specialist children's hospital in the nearest city. Thirteen parents were interviewed using a semi-structured interviewing technique, with the intention of answering the following research questions:

- What were the feelings of the parents immediately after the injury occurred?
- How did the experiences of the family once admitted to hospital affect their feelings?
- Did the injury affect the parent's view of their relationship with their child?
- How did the injury affect their safety behaviours within the home?

The study utilised a qualitative research method, interpretive description, to obtain and analyse rich descriptions of the reality of caring for a burn injured child. The data obtained from answering the research questions was then analysed in order to identify themes that could be seen as shared across the different accounts.

These themes were grouped into two main categories: the first category was identified from the responses to the research questions regarding changes in the parent/child relationship and safety practices; the second was in regard to the parents' experience of the healthcare they and their child experienced.

9.4 Study findings

9.4.1. Formulation of the parental adaptation model

From the responses to the research questions regarding changes in the parent/child relationship and safety practices, it was possible to identify themes around how the parents adjusted to the reality of caring for a burn injured child. I have therefore been able to suggest a model for parental adaptation in three stages. These stages are distinct but interconnected, so parents can move from one stage to the next, but then move back to an earlier stage if their situation or that of their child changes.

Through analysis of their narratives, I was able to identify a temporal element in the adaptation journey for the family. Parents entered each of the stages at particular times in their child's recovery from the burn injury. Therefore, it could be seen that in the early stages of treatment and recovery, parents were in the holding stage, where they talked of an overwhelming desire to hold the child for comfort and to reduce distress. It would appear that holding a distressed child close to try to comfort them is a normal parental instinct, and indeed I describe this very natural desire as 'instinctive holding'. However, I go on to suggest that parents also make strenuous efforts to be close to their child to ensure that they are identified as pre-eminent in the child's life. This type of 'intentional holding' is, I would argue, an attempt to regain some of the power that the parents may feel that they have lost as a result of the child's injury.

Once the child had been discharged from the hospital ward, it was possible from the interview data to identify the next stage of the adjustment process – guarding. As I described in Chapter 5 of this thesis, parents described how they felt compelled to guard their child from further injury and from the home environment where often the child had become injured in the first place. Their motives for guarding the child were mixed; clearly they were concerned that their child might go through more distressing treatment if they were injured again. However, the participants revealed that they felt, because they had 'allowed' their child to be injured before, they were under greater professional scrutiny, and needed to prove they could protect their child from another injury.

In the second part of the guarding stage, ‘guarding from the environment’, I was able to identify that parents had changed their view of their home as a safe place to one that held hidden dangers. Some of the parents described themselves as having become paranoid about safety, and were very clear that it had taken experience of the injury to change their awareness of safety. For a number of the parents interviewed, burn injury had also led them to believe that their child could be vulnerable to dirt and infection in the environment.

However, it was evident that despite their efforts to make the home environment safer, they still wanted reassurance from professionals that there was an element of chance in children’s accidents. Parents seemed to want some agreement that ‘accidents happen’, and therefore they could not be completely blamed for the injury. This was also an element noted in the findings on parental expectations of nurses on the acute paediatric ward, where parents almost seemed to seek absolution from their guilt that the injury had occurred.

Their experiences had also led the participants to develop a greater awareness of what they believed to be the vulnerability of children to the world. In exploring this theme, I suggest that recent concerns about risk to children reported in the media have increased pressure on parents to be seen to be protecting their children from harm.

The final stage of parental adaptation to their child's burn injury, defending, was entered at a later stage in the child's recovery. During this stage, parents described their attempts to prevent both the child and the family from being shamed at the appearance of the burn injury. It was evident that the burn injury scarring served as an ongoing reminder to themselves and others that they had 'allowed' the child to become injured. A particularly important element in this was concerned with parents coming to terms with having 'lost' the perfect child that they had before the burn injury, and their realisation that the burn injury scarring will have an impact as the child grows into adolescence and adulthood.

In this final stage, I also describe how parents reveal determination that their child will live as normal a life as possible, despite the burn injury. They seem very clear that they wish to avoid seeing their child as a victim, and are prepared to work hard at ensuring that their children are able to develop and socialise as any other adolescent.

9.4.2. Comparison with an existing model

While carrying out the literature search for this study, I was able to identify that other authors had attempted to formulate a coherent model for family adjustment to burn injury during the recovery process. Watkins et al (1996) build on earlier work to propose a model of family internal adaptation to burn injury, which was formulated from observations of the behaviour and reactions of family members while their

mainly adult relative was an in-patient on a burns unit. Using case studies to illustrate their discussion, the authors identified four phases in adaptation: crisis, control, commitment and consequences. The detail of this is described on page 34 of this thesis.

It is apparent that this suggested model has some relevance to the adaptation model that I have introduced in this thesis; however there are some important differences. The authors, clinicians in a burns unit, use three case studies to illustrate typical behaviours and responses in each of the stages of adaptation that they describe. One of the case studies describes the mother of a seven-year-old girl; the other two spouses of adult burn injury patients. However, unlike the study reported in this thesis, the individuals in the case studies were not interviewed in order to have their feelings and views used to develop the theory; they are simply used as examples of behaviour that relatives may show in each of the phases of adaptation, and how they might interact with health professionals. It is not evident from the article whether the authors observed the family members they describe as part of a specific observational study, or even if they were composite case studies made up of a variety of examples that they had seen.

Watkins et al (1996) describe the issues that the family member is likely to be concerned with, and the common emotional and behavioural responses to these that the family member may demonstrate. However, as they did not ask the family members themselves to identify their concerns, or to talk about their reactions, the meanings the authors are able to give to the stories they use are very limited. In

contrast, the model proposed in this thesis was formed from analysis of the narratives of the parents who had lived the experience of caring for a burn-injured child. As they described how they felt that their relationship with their child had changed as a result of what had happened, it was possible to identify the three stages of adaptation by interpretation of the meaning of their statements about their feelings and actions as their child recovered from the injury.

Although Watkins et al (1996) use one example of the parent of a seven year old child in order to illustrate their theory, it is evident that in general they are describing how an adult relationship needs to adapt in order to continue in the context of burn injury recovery, a stage they refer to as 'consequences'. They discuss the possible need to re-negotiate the relationship in the light of the trauma of caring and being cared for, and state that in some cases this re-negotiation has led to the family member withdrawing from the relationship. I would suggest that re-negotiation in the case of a parent and child relationship is more difficult. However, throughout the parental adaptation process proposed in this thesis, the parent is having to come to terms with the 'loss' of the child they had before the injury, and learn to adapt in order to cope with a new way of parenting.

It can be seen that both models have a place in helping to understand how family members adapt to the reality of burn injury. However, I would suggest that the model for parental adaption that has been proposed in this thesis is more applicable to the very different experience of caring for a burn injured child, with the challenge of supporting the child to grow to adulthood and independence.

9.4.3 Parents' experience of healthcare

Themes were identified around the parents' experience of the healthcare they and their child received during the time that the child was being treated as an inpatient, but also once the child had been discharged. This helped to formulate an understanding of how the attitude and skills of staff affected parents as they came to terms with their feelings immediately after the injury and during their time on the ward with their child.

The participants revealed they wanted their child to be treated as special by the nursing staff despite the demands of a busy ward. They revealed appreciation of the role of the named nurse, and used specific examples of how the involvement of one or two professionals throughout their child's inpatient stay was helpful both for the child and the wider family.

Parents also revealed that they needed their child to be cared for in the context of the family, and for some participants there was a desire to be cared for in their own right. They also demanded understanding that parents also had commitments and responsibilities outside the hospital, and that they would have welcomed some support in coping with these. However, for the majority of participants, it was evident that these expectations were met during their time on the ward.

In addition, they expected staff to demonstrate a high level of skill in caring for their child, and revealed that they had very rapidly gained knowledge of how technical procedures should be carried out. The fact that parents were so aware of skilful care was interesting, showing that professionals may not appreciate how quickly lay people can learn what to look for in clinical procedures. Participants were also very clear in wanting to regain some of their faith in themselves as parents by becoming partners in the care of their child. When this was facilitated and supported it was evident that it played a large role in helping parents to adjust.

9.4.4 How health professionals can support parental adaptation

It is evident that, if handled well, parental adaption can have a positive effect on the physical and psychological recovery and development of the child, leading to successful integration into adult life (Barnum et al 1998, Rossman and Gamble 1997). If the adjustment is not successful, and the family experiences greater difficulties, the chance that a severely burn injured child will meet his full potential is reduced (Blakeney et al 1990). As has already been reported, families who can be seen as already vulnerable are more likely to experience burn injury (Delgado et al 2002, O'Connor et al 2000, Alwash and McCarthy 1988). It is therefore of even greater importance that health professionals are pro-active in recognising and supporting parents through the adaptation process.

In Chapter 8 of this thesis I discuss how health professionals can help parents to adapt positively to parenting a burn injured child. The results from data analysis

reveal that support is not always consistent, and it may well be that this is because of lack of understanding of the importance of each stage. Therefore the chapter contains discussion on how health professionals can best support parents in all the stages of adaptation.

The first section, 'Helping parents to be there', contains a discussion on how health professionals can support parents to be physically close to their children, but also to ensure that the parents are involved in the child's care and in decision making about the child. Given the importance of this stage, I explore how parents can have greater involvement during treatment, both in order to comfort the child, but also to help parents to regain feelings of competence.

The second section, 'Helping parents to be in charge', contains discussion on how parents looked to health professionals, in particular health visitors, to validate their parenting ability, and to keep their child safe. Parents seemed to feel that only by being able to guard their child when at home will their moral authority as protectors of their children be re-established, so they look to healthcare professionals to provide them with support in making the home environment safer.

I am also able to present evidence from the interview data that, in contrast to some other studies (Peckover 2002, Foster and Mayall 1990), parents seemed to welcome the surveillance role of the health visitor in respect to child safety and protection, and invite judgement on their parenting ability. In reality though, for the families in this study, health visitor involvement appeared minimal. It is possible to speculate that, in

general, health visitors may feel reluctant to visit following an injury as they are concerned parents may assume they are 'checking up' on their clients. For example, Reynolds (1996: 99) reports on one health visitor 'building up courage' to discuss a recent injury with a client. However, the evidence from my study seems to be that the participants welcome the surveillance role of the health visitor, and also look to the health visitor for their support in coming to terms with the injury. Therefore, the involvement of the health visitor both in the short term to help parents regain confidence and in the longer term to help them cope with developmental changes seems to be vital.

In the final section, 'helping parents to defend', I present a discussion on how health professionals can assist parents in coming to terms with the appearance of their child's burn injury, in particular by the extensive use of photography. There is evidence from the interview data that ward staff employed photographs as an educational tool to prepare parents for treatment procedures, as well as to inform parents who had not been as closely involved in their child's medical care. Although there is clearly evidence that photographs are being used at a practice level to support care, it is possible that nursing staff are not fully aware of their beneficial effect for parents in looking back at how far their child's healing had come. It seems certain that feeling positive about their child's healing contributes greatly to the ability of parents to come to terms with the loss of their 'perfect child'.

Parents also revealed their desire to ensure that their child grows up to enjoy a full, normal life despite the burn injury, and their determination that their child will not be

seen or see themselves as a victim. The role of professionals and the voluntary sector in rehabilitation and family support is evident, but it can be seen that support to families may need to be carefully planned to ensure that information and support is tailored to their needs at each stage of their child's development.

Bearing in mind these findings, it is possible to identify that parents go through a definite process of adaptation to caring for a burn injured child and that professionals have a vital role in supporting this adaptation. However, as the evidence is that families affected by burn injury are more likely to be struggling to cope with other issues such as poverty, poor housing and mental health issues that make parenting a challenge, it is important to identify implications of the model of parental adjustment for policy makers and practitioners as they look at how services to the families of burn injured children should be improved.

9.5 Implications of this study

9.5.1 Implications for policy

The results of this study demonstrate that burn injury has a profound effect on the families affected. All the participants expressed the need for support both while their child was undergoing treatment, and afterwards as they adapted to the new reality of parenting a burn injured child.

9.5.1.1 Support for families under pressure

The evidence that burn injury is more likely in families where there are issues around mental health problems, low income and poor, overcrowded housing suggests that measures designed to reduce these risk factors will have a positive effect on the numbers of burn injuries (Edwards et al 2006, Roberts and Pless 1995). Recent legislative changes on tap water temperature have ensured that newly fitted installations do not discharge water hot enough to severely scald (Scottish Building Standards Agency 2005), and this is a positive measure supported by many injury prevention charities. However the biggest risk of scald injury for children is from hot drinks (DTI 1999), suggesting that what is happening within the home at the time of the injury is probably highly relevant. Measures that support families under stress to improve their income, housing and ability to cope may therefore be more effective than educational initiatives alone.

9.5.1.2 Specialist burn units

Parents expressed that staff involved in their child's care should be highly skilled, not only in the technical elements of care, but also in interpersonal communication in working with families who are struggling with grief, shock and guilt. These skills are most likely to be found in specialist burns units where evidence indicates that the outcomes for burned children are much better (National Burn Care Review Committee 2001). It is therefore desirable that all significantly burn injured children should be nursed in specialised paediatric burn units.

9.5.1.3 Rehabilitation

It is evident that long term support for families is in general provided by the voluntary sector through charities and other bodies, although with the valuable and essential support of burn injury professionals. The results from this study demonstrate that burn injury has long lasting effects on parenting. Therefore support for families becomes important to ensure good outcomes for these children during adolescence and early adulthood. It would therefore be valuable for all families to be offered group or individual support through the Health Service. The National Burn Care Review Committee (2001) also gave a recommendation that burn camps should be funded by the Health Service and their contribution to the rehabilitation and support of burn injured young people audited to identify and disseminate best practice.

9.5.1.4 Creating safe environments

Recent concerns regarding the physical activity levels of young people have been raised because of recognition that few children are permitted the freedom to play outside due to safety concerns (Gill 2007). As we seem to be living in an increasingly risk averse society (Furedi 2002, Warner 2006) it is likely to be ever more important that local authority and government work together to create safe environments and neighbourhoods where children and parents are able to learn to manage risk. Bearing in mind that it is often perceived rather than actual dangers which prevent parents from allowing their children to play outside freely, there may be a place for government to raise awareness of the dangers of not allowing children to learn to cope with risk.

9.5.2 Implications for practice

9.5.2.1 Support for all family members

In this thesis I have proposed a model for parental adaptation to burn injury based on interpretation of the experience of parents. It seems most evident that adjustment for parents is a process; therefore they need help and support at all stages. This support needs to be both practical and psychological, and needs to be provided for the whole family. It was relevant that one father pointed out that all the support provided for the family was based around the mother who was resident. The parent, or other family member, left at home caring for other children, needs as much help and support as the parent who stays with the child, as do the other siblings. Ensuring that the wellbeing of the child and the whole family is constantly taken into account when planning services will mean that no member feels that they are ignored.

9.5.2.2 The role of health visiting

Research evidence suggests that the primary health care team and health visitors in particular, have a prominent role in childhood injury prevention and support (Roberts et al 1995, Kendrick et al 1999, Kendrick et al 1995, Carter et al 1995). This evidence suggests that the role has two elements: pro-active, where the health visitor routinely provides information or equipment to help parents to keep their child safe; and reactive, following a specific injury episode when the health visitor may provide family support and advice to prevent further injuries.

My analysis of the interview data for this study suggests that the participants expected that health visitors would fulfil this pro-active role, and most participants could recall occasions when their health visitor provided written and verbal information about safety as part of routine contact with the family. The provision of information regarding the purchase and use of safety equipment was also mentioned. The participants evidently found the information to be helpful and relevant to their needs, and they had no difficulty in recalling the advice that they had been given.

Of perhaps greater importance to this set of parents was the role of the health visitor in providing support for the family after an injury had occurred. As indicated in the literature review chapter of this thesis (page 28), much of the available published evidence is in relation to routine post-accident visiting rather than longer-term support for families who have experienced a more severe injury.

It is recognised that families may be sceptical of the motives behind the visit, suspecting that the health visitor's presence indicates they may be under suspicion (Combes 1991, Reynolds 1996). I have already suggested earlier in this chapter (page 229) that because of an assumption of parental suspicion, health visitors may feel ambivalent about contacting a family post-injury. Their concern may be that the parents will see a visit as an unwelcome expression of the health visitor's perceived role in policing the family (Dingwall and Robinson 1993).

However, as discussed in Chapter 8 (page 203), far from resenting the surveillance role of the health visitor, the parents in my study seemed to welcome it as a validation of their parenting. Combining this finding with the evidence provided by Machen (1996), who found that mothers felt empowered rather than judged by their health visitors, it seems likely that the participants would have welcomed the help and support of their health visitor once their child had been discharged from hospital. The fact that the parents in my study had evidently welcomed their health visitor's advice in regard to safety prior to the injury adds further weight to this argument. However, it was concerning that none of the participants had contact from their health visitor in the time immediately following leaving the hospital, and at least one family had to actually approach their health visitor to ask for a visit.

It is possible that the lack of health visitor contact immediately following the injury might be explained by poor communication in the primary healthcare team or lack of information from the specialist hospital. However, I would suggest that health visitors may also feel ill-equipped for coping with the parent's guilt feelings about the injury, especially if they feel strongly that it might have been avoided. This element could be an interesting subject to be explored in future research.

Lack of time, caseload pressures and covering work for absent colleagues may also contribute to lack of intervention. Hilton (2002) and Carter et al (1992) both found that these reasons were identified as most important when health visitors discussed why they failed to engage in effective pro-active injury prevention interventions. It

is likely that recent staff shortages and increased caseloads have reduced the capacity of health visitors to carry out the intensive support work that they might wish. However, support of parents by knowledgeable staff to ensure successful adaptation to their child's burn injury should be seen as a priority.

9.6 Future research

During investigation of the issues around burn injury it has been possible to identify a number of opportunities for further research on this subject. Some of these are in relation to how families adjust over longer periods of time, but it can also be seen that some of the techniques used in practice could be investigated and disseminated more widely to improve the care of families.

9.6.1 Long-term adjustment of the parents of burn injured children in adulthood

In order to study the long term applicability of the parental adaptation model it would be interesting to do a longitudinal study of families of children who had been burn injured at less than five years of age, following them through into adulthood. This could give valuable insight into how their parents faced the challenge of protecting their children from danger, whilst also trying to ensure that they lived a normal life.

9.6.2 Parental presence in the recovery room

The discussion on parental presence in the anaesthetic room identified that some preliminary small-scale studies had been carried out on allowing parents to be present in the recovery room post-operatively (Smith and Bassett 1996, Hall et al 1995). The results of these studies were perceived to be positive. Considering that a number of the parents had found being parted from their child while in theatre very challenging, further research on the benefits and limitations of allowing parents to be

present immediately post-operatively may increase understanding of this potential change in practice. As burn injured children often face multiple surgical procedures, looking at this group in particular may provide good insights for paediatric surgery in general.

9.6.3 The use of photography in burn injury

In Chapter 8 I discussed that photography was used as a tool for educating and supporting parents to cope with the reality of their child's burn injury scarring. It was evident that although some research had been done on the use of photography in burn injury, it had largely been concerned with how photography could be used to improve the technical care of the patient, rather than a tool to support families (Nelson et al 2006, Van et al 2004). Parents in my study found being able to look at a photographic record of their child's burn injury as it healed to be very helpful, especially if they had felt unable to look at the burn injury during dressing changes. A more detailed exploration of this method of education and support could reveal valuable results.

9.7 Reflection of the personal aspects of the research process

Researching the effects of burn injury on the family proved to be an invaluable personal learning journey for me as a nurse, health visitor, fledgling academic and, probably most importantly, as a mother. Undertaking the literature review at the start of the research process proved to be only the starting point in appreciating what

was already known about the subject, as I found my skills in critical appraisal of the literature developed throughout the research process alongside my understanding of the impact of injury on children.

Interviewing the participants allowed me a privileged entrance into their lives at a time of great stress and difficulty. Parents were able to recall with significant clarity and detail their feelings and reactions at the time of their child's injury. Their willingness to reveal and share these insights resulted in me feeling enormous sympathy and respect for the participants as fellow parents.

Carrying out this research and identifying the parental adaptation model has been challenging and exciting. The skills I have developed will no doubt be of great benefit in the future.

9.8 Conclusion

This study has contributed to an understanding of the complex and important issue of family adjustment to childhood burn injury. In it, I have proposed that parents go through a definite process of adaptation to the new reality of caring for a burn injured child.

Considering that families affected by burn injury may already be coping with challenging life circumstances, the intervention and support offered by health professionals at every stage of adaptation becomes even more important in order for

parents to provide the sensitive, responsive parenting that their burn injured child needs to reach full potential.

Health professionals increasingly look for specific evidence that will inform their practice; this study provides theory that can be used as a basis to plan specific interventions that will support and help families on their journey of recovery.

REFERENCES

- Adams C Girolami P Joseph E Sauvageot, S Slater H (2002) Use of a token reinforcement system to promote appropriate behavior at a pediatric burn summer camp *Journal of Burn Care and Rehabilitation* 23 297–304
- Acton A (2004) When we leave hospital: a patient's perspective of burn injury *British Medical Journal* 329 504-506
- Acton A Mounsey E Gilyard C (2007) The Burn Survivor Perspective *Journal of Burn Care and Research* 28(4) 615-620
- Alsop-Shields L Mohay H (2001) John Bowlby and James Robertson: theorists, scientists and crusaders for improvements in the care of children in hospital *Journal of Advanced Nursing* 35(1) 50-58
- Alwash R McCarthy M (1998) Accidents in the home among children under five-ethnic differences or social disadvantage *British Medical Journal* 296 1450-1452
- Angermeier J (1991) A desensitization process to facilitate first visits between burn-scarred parents and young children *Journal of Burn Care and Rehabilitation* 12 344-355
- Anthony K Gil K Schanberg L (2003) Brief Report: Parental perceptions of child vulnerability in children with chronic illness *Journal of Pediatric Psychology* 28(3) 185-190
- Appleton J (1995) Analysing qualitative interview data: addressing issues of validity and reliability *Journal of Advanced Nursing* 22(5) 993-997
- Armstrong D (1993) From clinical gaze to regime of total health IN Beattie A Gott M Jones L Sidell M (ed) *Health and Wellbeing – a reader* Open University Press London
- Arnoldo B Crump, D Burris, A Hunt, J Purdue, G (2006) Self-Esteem Measurement Before and After Summer Burn Camp in Pediatric Burn Patients *Journal of Burn Care Research* 27 786–789
- Baker C Wuest J Stern PN (1992) Method slurring: the grounded theory/phenomenology example *Journal of Advanced Nursing* 17 (11) 1355-1360
- Barnett D Clements M Kaplan-Estrin M Fialka J (2003) Building New Dreams. Supporting parent's adaptation to their child with special needs *Infants and Young Children* 16(3) 184-200

Barnum D Snyder CR Rapoff MA Mani M Thompson R (1998) Hope and social support in the psychological adjustment of children who have survived burn injury and their matched controls *Children's Health Care* 28 278-287

Beck CT (1993) Qualitative research: the evaluation of its credibility, fittingness and auditability *Western Journal of Nursing Research* 15(2) 263-266

Bergum B (1991) Being a Phenomenological Researcher IN Morse (ed) *Qualitative Nursing Research: A Contemporary Dialogue* Sage London

Bialoskurski M Cox C Wiggins R (2002) The relationship between maternal needs and priorities in a neonatal intensive care environment *Journal of Advanced Nursing* 37(1) 62-69

Bijur PE (1995) What's in a name? Comments on the use of the terms 'accident' and 'injury' *Injury Prevention* 1 9-11

Bion (1993) *Attention and Interpretation* Tavistock London

Blakeney P Portman S Rutan R (1990) Familial values as factors influencing long-term psychological adjustment of children after severe burn injury *Journal of Burn Care and Rehabilitation* 11 472-475

Blakeney P Moore P Broemeling L Hunt R Herndon D Robson M (1993a) Parental stress as a cause and effect of pediatric burn injury *Journal of Burn Care and Rehabilitation* 14 73-79

Blakeney P Meyer W Moore P Murphy L Broemeling L Robson M Herndon D (1993b) Psychosocial sequelae of pediatric burns involving 80% or greater total body surface area *Journal of Burn Care and Rehabilitation* 14 684-689

Blakeney P Meyer W Robert R Desai M Wolf S Herndon D (1998) Long-Term Psychosocial Adaptation of Children Who Survive Burns Involving 80% or Greater Total Body Surface Area *Journal of Trauma-Injury Infection & Critical Care* 44(4) 625-634

Blakeney P Partridge J Rumsey N (2007a) Community Integration *Journal of Burn Care and Research* 28(4) 598-601

Blakeney P Rosenberg L Rosenberg M Fauerbach J (2007b) Psychosocial recovery and reintegration of patients with burn injuries IN Herndon D(ed) *Total Burn Care* Elsevier Philadelphia

Blesch P Fisher M (1996) The impact of parental presence on parental anxiety and satisfaction *Journal of the Association of Operating Room Nurses* 63(4) 761-768

Bowlby J (1980) *Attachment and Loss* Penguin London

- Callery P (1997a) Paying to participate; financial, social and personal costs to parents of involvement in their children's care in hospital *Journal of Advanced Nursing* 25(4) 746-752
- Callery P (1997b) Caring for parents of hospitalized children: a hidden area of nursing work *Journal of Advanced Nursing* 26(5) 992-998
- Callery P Luker K (1996) The use of qualitative methods in the study of parents' experiences of care on a children's surgical ward *Journal of Advanced Nursing* 23(2) 338-345
- Calman L (2004) *Patients' views of nurses' clinical competence: a grounded theory approach* Unpublished PhD thesis University of Edinburgh
- Cameron J Bond M Pointer S 1996 Reducing the anxiety of children undergoing surgery: Parental presence during anaesthetic induction *Journal of Paediatrics & Child Health*. 32(1) 51-56
- Carter C Meckes L Pritchard L Swenson S Wittman P Velde B (2004) The Friendship Club : An after-school program for children With Asperger's Syndrome *Family Community Health* 27(2) 143-150
- Carter Y Bannon M Jones P (1992) Health visitors and child accident prevention *Health Visitor*. 65(4) 115-7
- Carter Y Morgan P Lancashire R (1995) General practitioners' attitude to child injury prevention in the UK: a national postal questionnaire *Injury Prevention* 1 164-168
- Caty S Ritchie J Ellerton M (1989) Helping hospitalised preschoolers manage stressful situations: the mother's role *Children's Health Care* 18(4) 202-209
- Child Accident Prevention Trust (2002) *Children's Accidents: Facts and Figures* Child Accident Prevention Trust, London
- Cescutti-Butler L Galvin K (2003) Parents' perceptions of staff competency in a neonatal intensive care unit *Journal of Clinical Nursing* 12 752-761
- Chedekel D Tolia C (2001) Adolescents' Perceptions of Participation in a Burn Patient Support Group *Journal of Burn Care and Rehabilitation* 22 301- 306
- Clamp M Kendrick D (1998) A randomised controlled trial of general practitioner safety advice for families with children under 5 years *British Medical Journal* 316 1576-1579
- Colley E (1994) Different backgrounds, different information needs- awareness of home safety issues among parents of pre-school children *Professional Nurse* 9 (12) 832-834

- Combes G (1991) *You can't watch them twenty-four hours a day* Child Accident Prevention Trust London
- Corlett J Twycross A (2006) Negotiation of parental roles within family-centred care: a review of the literature *Journal of Clinical Nursing* 15 1308-1316
- Corrarino J Walsh P Boyle M Anselmo D (2000) The Cool Kids Coalition: A Community Effort to reduce scald burn risk in children *American Journal of Maternal and Child Nursing* 25 (1) 10-17
- Coyne I (1996) Parent participation: a concept analysis *Journal of Advanced Nursing* 23 (4) 733-740
- Cox E Call S Williams N Reeves P (2004) Shedding the Layers: Exploring the Impact of the Burn Camp Experience on Adolescent Campers' Body Image *Journal of Burn Care and Rehabilitation* 25 141-147
- de la Cuesta C (1994) Relationships in health visiting: enabling and mediating *International Journal of Nursing Studies* 31(5) 451-459
- Dally A (1982) *Inventing Motherhood-The consequences of an ideal* Hutchinson London
- Darbyshire P (1994) *Living with a sick child in hospital: the experience of patients and nurses* Chapman and Hall London
- Davison S Simpson C (2006) Hope and advance care planning in patients with end stage renal disease: qualitative interview study *British Medical Journal*, doi:10.1136/bmj.38965.626250.55
- Delgado J Ramirez-Cardich ME Gilman RH Lavarello R Dahodwala N Bazan A Rodriguez Cama RI Tovar M Lescano A (2002) Risk factors for burns in children: crowding, poverty and poor maternal education *Injury Prevention* 8 38-41
- Department of Trade and Industry (1999) *Burns and scalds accidents in the home* Consumer Affairs Directorate DTI London
- Dellve L Samuelsson L Tallborn A Fasth A Hallberg (2006) Stress and well-being among parents of children with rare diseases: prospective intervention study *Journal of Advanced Nursing* 53(4) 392-402
- Dingwall R Robinson (1993) Policing the family? Health visiting and the public surveillance of private behaviour IN Beattie A Gott M Jones L Sidell M (ed) *Health and Wellbeing – a reader* Open University Press London

- Dixon – Woods M Seale C Young B Findlay M Heney D (2003) Representing childhood cancer: accounts from newspapers and parents *Sociology of Health and Illness* 25(2) 143-164
- Dooley F (1999) The named nurse in practice *Nursing Standard* 13(34) 33-38
- Edwards P Green J Roberts I Lutchman S (2006) Deaths from injury in children and employment status in family; analysis of trends in class specific death rates *British Medical Journal*, doi:10.1136/bmj.38875.757488.4F
- Espezel H Canam C (2003) Parent- nurse interaction: care of hospitalized children *Journal of Advanced Nursing* 44(1) 34-41
- Evans M (1994) An investigation into the feasibility of parental participation in the nursing care of their children *Journal of Advanced Nursing* 20 477-482
- Evans SA (2001) Banning the A word: where's the evidence *Injury Prevention* 7, 172-175
- Feldman KW Schaller RT Feldman JA McMillon M (1998) Tap water scalds in children *Injury Prevention* 4 238-242
- Fonagy P (2001) Attachment theory and psychoanalysis Other Press New York
- Foster M Mayall B (1990) Health visitors as educators *Journal of Advanced Nursing* 15 286-292
- Fukinishi I (1998) Post-traumatic stress symptoms and depression in mothers of children with severe burn injury *Psychological Reports* 83 331-335
- Funck-Brentano I Dalbanb C Vebera F Quartiera P Hefeza S Costagliolab D Blanchea S (2005) Evaluation of a peer support group therapy for HIV-infected adolescents *AIDS* 19 1501–1508
- Furedi F (2002) *Paranoid Parenting* Chicago Review Press
- Gaffney P (2000) The domestic iron. A danger to young children *Journal of Accident and Emergency Medicine* 17 199-200
- General Registrar of Scotland (2006) *Scotland's Population 2005* General Register Office for Scotland
- Gill T (2007) *No Fear: Growing up in a risk averse society* Calouse Gulbenkion Foundation London
- Girasek DC (1999) How members of the public interpret the word 'accident' *Injury Prevention* 5 19-25

Green M Solnit A (1964) Reactions to a threatened loss of a child: a vulnerable child syndrome *Pediatrics* 34 58-66

Gross D (1996) What is a good parent? *American Journal of Maternal/Child Nursing* 21(4) 178-182

Guardian/ICM (2000) The Guardian/ICM Monthly Poll <http://www.icm.research.co.uk/reviews/2000/guardian-poll-august-2000.htm>

Guldborg H (2007) Are children being held hostage by parental fears? *Spiked online* <http://www.spiked-online.com/index.php/site/article/3465/>

Hall E (2005) Danish parents' experiences when their new born or critically ill small child is transferred to the PICU – a qualitative study *Nursing in Critical Care* 10(2) 90-97

Hall P Payne J Stack C Stokes M (1995) Parents in the recovery room: survey of parental and staff attitudes *British Medical Journal* 310 (6973) 163-164

Hapgood R Kendrick D Marsh P (2000) How well do socio-demographic characteristics explain variation in childhood safety practices *Journal of Public Health Medicine* 17 (2) 307-311

Hays S (1996) *The Cultural Contradictions of Motherhood* Newhaven London

Haycock-Stuart E (1999) Sense and Susceptibility: How mothers view accidental injury risk and develop safety strategies for pre-school children Unpublished PhD thesis University of Edinburgh

Heptinstall E (1996) *Healing the hidden hurt- the emotional effect of children's accidents* Child Accident Prevention Trust London

Hettiaratchy S Dziewulski P (2004) Pathophysiology and types of burns *British Medical Journal* 328(7453) 1427-1429

Hill Bailey P (1997) Finding your way around qualitative methods in nursing research *Journal of Advanced Nursing* 25 18-22

Hilton S (2002) 'Prevention is better than cure' A qualitative study exploring health visitors' perceptions about their health promotion contribution to childhood safety in the home. Unpublished MSc Thesis Strathclyde University

Hoghugh M Speight A (1998) Good enough parenting for all children – a strategy for a healthier society *Archives of Disease in Childhood* 78(4) 293-296

Holloway I Fulbrook P (2001) Revisiting qualitative enquiry: Interviewing in nursing and midwifery research *NT Research* 6(1) 539-550

Holloway I Wheeler S (1996) *Qualitative Research for Nurses* Blackwell Scientific Publications Oxford.

Holmes J (1993) *John Bowlby and Attachment Theory* Routledge London

Hopia H Tomlinson P Paavilainen E Astdt-Kurki P (2005) Child in hospital: family experiences and expectations of how nurses can promote family health *Journal of Clinical Nursing* 14 212-222

Hu X Wesson D Parkin P Rootman I (1996) Pediatric injuries- parental knowledge, attitudes and needs *Canadian Journal of Public Health* 87 (2) 101-105

Hunt J Arnoldo B Purdue G (2007) Prevention of burn injuries IN Herndon D(ed) *Total Burn Care* Elsevier Philadelphia

Information Statistics Division Scotland (2006) Unintentional Injuries in Children http://www.isdscotland.org/isd/uichildren.jsp?pContentID=4428&p_applic=CCC&p_service=Content.show&

Jack S DiCenso A Lohfeld L (2005) A theory of maternal engagement with public health nurses and family visitors *Journal of Advanced Nursing* 49(2) 182-190

Jeffery SLA Cubison TCS Greenaway C Gilbert PM Parkhouse N (2000) Warming milk, a preventable cause of scalds in children *British Medical Journal* 320 235

Jenkins H Stanwick R (1991) A survey of Pediatric Discharge Educational Programs in North American Burn Units *Journal of Burn Care and Rehabilitation* 12 243-248

Johansen M Wootton R Kimble R Mill J Smith A Hockey A (2004) A feasibility study of email communication between the patient's family and the specialist burns team *Journal of Telemedicine and Telecare* 10 53-56

Johnson BD Grossman DC Connell FA Koepsell TD (2000) High risk periods for childhood injury amongst siblings *Pediatrics* 105 (3) 562-568

Johnson M Webb C (1995) Rediscovering unpopular patients: the concept of social judgement *Journal of Advanced Nursing* 21(3) 466-475

Kai J (1996) Parent's difficulties and information needs in coping with acute illness in pre-school children: a qualitative study *British Medical Journal* 313 984-986

Kain Z Caldwell-Andrews A Mayes L Wang S Krivutza D Le-Dolce M (2003) Parental Presence during induction of anaesthesia Physiological effects on parents *Anesthesiology* 98 98-64

Kain Z Caldwell-Andrews A Krivutza D Weinberg M Wang S Gaal D (2004) Trends in the practice of parental presence during induction of anesthesia and the use of

preoperative sedative premedication in the United States 1995-2002: results of a follow-up national study *Anesthesia and Analgesia* 98 1252-1259

Kain Z Caldwell-Andrews A Mayes L Weinberg M Wang S MacLaren J Blount R (2007) Family-centered preparation for surgery improves perioperative outcomes in children: a randomized controlled trial. *Anesthesiology* 106(1) 65-74

Keddy BA (1994) Commentary on Beck C (1994) Reliability and validity issues in phenomenological research *Western Journal of Nursing Research* 16(3) 263

Kendall-Grove K Ehde D Patterson D Johnson V (1998) Rates of dysfunction in parents of pediatric patients with burns *Journal of Burn Care and Rehabilitation* 19 312-316

Kendrick D Marsh P Fielding K Miller P (1999) Preventing injury in children: cluster randomised controlled trial in primary care *British Medical Journal* 318 980-983

Kendrick D Marsh P Williams E (1995) How do practice nurses see their role in childhood injury prevention? *Injury Prevention* 1 159-163

Kerruish N Settle K Campbell-Stokes P Taylor, B (2005) Vulnerable Baby Scale: Development and piloting of a questionnaire to measure maternal perceptions of their baby's vulnerability *Journal of Paediatric Child health* 41 419– 423

King J Klassen T LeBlanc J Bernard-Bonnin A Robitaille Y Pham B Coyle D Tenenbein M Pless B (2001) The Effectiveness of a Home Visit to Prevent Childhood Injury *Pediatrics* 108(2) 382-388

Kristensson-Hallstrom I Nilstun T (1997) The parent between the child and the professional – some ethical implications *Childcare Health and Development* 23 (6) 447-455

Kristensson-Hallstrom I (1999) Strategies for feeling secure influence parents' participation in care *Journal of Clinical Nursing* 8(5) 586-592

Knoll S Johnson J (2000) Uncertainty and Expectations: Taking care of a cardiac surgery patient at home *Journal of Cardiovascular Surgery* 14(3) 64-75

Koch T Harrington A (1998) Reconceptualizing rigour: the case for reflexivity *Journal of Advanced Nursing* 28(4) 882-890

Landolt M Grubenmann S Meuli M (2002) Family impact greatest: Predictors of quality of life and psychological adjustment in pediatric burn survivors *Journal of Trauma-Injury Infection and Critical Care* 53(6) 1146-1151

Larner S (2005) Common psychological challenges for patients with newly acquired disability *Nursing Standard* 19(28) 33-39

- Lawrence J Fauerbach J Heinberg L Doctor M (2004) Visible vs hidden scars and their relation to body esteem *Journal of Burn Care and Rehabilitation* (25) 25-32
- Lee J Herndon D (2007) The pediatric burned patient IN Herndon D (ed) *Total Burn Care* Elsevier Philadelphia
- Lincoln Y Guba E (1985) *Naturalistic Enquiry* Sage Beverly Hills
- Ling M Luker K (2000) Protecting children: intuition and awareness in the work of health visitors *Journal of Advanced Nursing* 32 (3) 572-579
- Lok S Menahem S (2004) Parental perception of small ventricular septal defects in childhood *Journal of Paediatrics and Child Health* 40 180-183
- Machen I (1996) The relevance of health visiting policy to contemporary mothers *Journal of Advanced Nursing* 24 350—356
- Macdonald M 2003 Seeing the Cage: Stigma and Its Potential to Inform the Concept of the Difficult Patient *Clinical Nurse Specialist* 17(6) 305-310
- MacLennan JD Kotelchuck M (2000) Parental prevention practices in the context of maternal depression *Pediatrics* 105 (5) 1090-1095
- Marsh P Kendrick D Williams EI (1995) Health visitor's knowledge, attitudes and practices in childhood accident prevention *Journal of Public Health Medicine* 17 (2) 193-199
- May KA (1991) Interview Techniques in Qualitative Research IN Morse (ed) *Qualitative Nursing Research: A Contemporary Dialogue* Sage London
- Melnik B Feinstein N (2001) Mediating functions of maternal anxiety and participation in care on young children's post-hospital adjustment *Research in Nursing and Health* 24 18-26
- Meyer WJ Blakeney P Moore P Murphy L Robson M Herndon D (1994) Parental well-being and behavioral adjustment of pediatric survivors of burns *Journal of Burn Care and Rehabilitation* 15 312-316
- Meyer W Blakeney P Russell W Thomas C Robert R Berniger F Holzer C (2004) Psychological problems reported by young adults who were burned as children *Journal of Burn Care and Rehabilitation* 25 98-106
- Miceli P Clark P (2005) Your patient – My child. Seven priorities for improving pediatric care from the parent's perspective *Journal of Nursing Care Quality* 20(1) 43-53

- Miles M Holditch-Davies D Shepherd H (1998) Maternal Concerns about parenting *American Journal of Maternal/Child Nursing* 23(2) 70-75
- Mitchell A Wesner S Garand L Gale D Havill A Brownson L (2007) A Support Group Intervention for Children Bereaved by Parental Suicide *Journal of Child and Adolescent Psychiatric Nursing* 20(1) 3-13
- Morse J (1995) Preserving self: from victim, to patient, to disabled person *Journal of Advanced Nursing* 21(5) 886-896
- Morse J (1991a) Qualitative Nursing Research: A Free for All IN Morse (ed) *Qualitative Nursing Research: A Contemporary Dialogue* Sage London
- Morse J (1991b) Strategies for Sampling IN Morse (ed) *Qualitative Nursing Research: A Contemporary Dialogue* Sage London
- Morrongiello B Dayler L (1996) A community based study of parent's knowledge, attitudes and beliefs related to childhood injuries *Canadian Journal of Public Health* 87 (6) 383-388
- Mott J (1999) Personal and family predictors of children's medically attended injuries that occurred in the home *Injury Prevention* 5 189-193
- Munhall PL (1988) Ethical considerations in qualitative research *Western Journal of Nursing Research* 10(2) 150-162
- Munro SA van Niekerk A Seedat M (2006) Childhood unintentional injuries: the perceived impact of the environment, lack of supervision and child characteristics *Child: Care, Health & Development* 32(3) 269-279
- National Burn Care Review Committee (2001) *Standards and Strategy for Burn Care: A review of burn care in the British Isles*
- Nelson L Boyle M Taggart I Watson S (2006) Are burns photographs useful? *Burns* 32 876-879
- Normandale S (2001) A study of mother's perceptions of the health visiting role *Community Practitioner* 74(4) 146-150
- Noyes J (1998) A critique of studies exploring the experiences and needs of parents of children admitted to paediatric intensive care units *Journal of Advanced Nursing* 28(1) 134-141
- O'Connor T Davies L Dunn J Golding J (2000) Distribution of accidents, injuries and illnesses by family type *Pediatrics* 106 (5) 68-79

Oiler Boyd C (1993) *Philosophical Foundations of Qualitative Research* IN Munhall P Oiler Boyd C (ed) *Nursing Research: A Qualitative Perspective* National League for Nursing New York

Peckover S (2002) Supporting and policing mothers: an analysis of the disciplinary practices of health visiting *Journal of Advanced Nursing* 38(4) 369-377

Piazza-Waggoner C Butcher M, Adams C Goldfarb I Slater H (2004) Assessing the relationship between locus of control and social competence in pediatric burn survivors attending summer camp *Journal of Burn Care and Rehabilitation* 25 349–356

Piira T Sugiura T Champion G Donnelly N Cole A (2005) The role of parental presence in the context of children's medical procedures: a systematic review *Child: Care, Health and Development* 31(2) 233-243

Polko L McMahon M (1998) Burns in pregnancy *Obstetric and Gynecological Survey* 53 50–56.

Pringle MK (1992) *The Needs of Children* Routledge London

Quayle KS Wick NA Gnauck KA Schootman M Jaffe DM (2000) Description of Missouri children who suffer burn injuries *Injury Prevention* 6 255-258

Raver C Leadbeater B (1999) Mothering under pressure: environmental, child and dyadic correlates of maternal self-efficacy among low-income women *Journal of Family Psychology* 13(4) 523-534

Reynolds L (1996) A qualitative evaluation of the post accident notification system to health visitors *Journal of Advanced Nursing* 23(1) 97-105

Rich A (1977) *Of Woman Born - Motherhood as Experience & Institution* Virago London

Rimmer R Foster K Bay C Floros J Rutter C Bosch J Wadsworth M Caruso D (2007a) The reported effects of bullying on burn-surviving children *Journal of Burn Care and Research* 15 484-489

Rimmer R Fornaciari G Foster K Bay C Wadsworth M Wood M Caruso D (2007b) Impact of a pediatric residential burn camp experience on burn survivors' perceptions of self and attitudes regarding the camp community *Journal of Burn Care and Research* 28 334-341

Rizzone L Stoddart F Murphy JM Kruger L (1994) Post-traumatic stress disorder in mothers of children and adolescents with burns *Journal of Burn Care and Rehabilitation* 15 158-163

Robert R Blakeney P Herndon D (2007) Maltreatment by burning IN Herndon D (ed) *Total Burn Care* Elsevier Philadelphia

Roberts H (1997) Not everything that counts can be counted: Qualitative research methods in interventions in injury *Archives of Diseases in Childhood* 76 487-489

Roberts H Smith SJ Bryce C (1995) *Children at Risk: Safety as a Social Value* Open University Press Milton Keynes

Roberts I (1996) Parental Supervision: a popular myth *Injury Prevention* 2 9-10

Roberts I Pless B (1995) For Debate: Social Policy as a cause of childhood accidents: the children of lone mothers *British Medical Journal* 311 925-928

Rogan F Scmied V Barclay L Everitt L Wyllie A (1997) 'Becoming a mother – developing a new theory of early motherhood *Journal of Advanced Nursing* 25(5) 877-885

Rolland J Walsh F (2006) Facilitating family resilience with childhood illness and disability *Current Opinion in Pediatrics* 18 527-538

Romino S Keatley V Secrest J Good K (2005) Parental presence during anaesthesia induction in children *Journal of Operating Room Nurses* 81(4) 780-792

Rose M Holzer C Tuden C Rosenberg M Herndon D Blakeney P (2005) Reported stress of parents of burned children differs on the Spanish and English versions of the Parenting Stress Inventory *Journal of Burn Care and Rehabilitation* 26 446-452

Rossmann BBR Gamble W (1997) Pre-schooler's understanding of physical injury: stressor, affect and coping appraisals *Children's Healthcare* 26 (2) 77-96

Rosenberg M Blakeney P Robert R Thomas C Holzer C Meyer W (2006) Quality of life of young adults who survived pediatric burns *Journal of Burn Care and Rehabilitation* 26 446-452

Sanders T Cogley C (2005) Identifying non-accidental injury in children presenting to A&E departments – an overview of the literature *Accident and Emergency Nursing* 13 130–136

Scheidt PC Brenner RA Rossi MW Clyman R Boyle KE (2000) Parental attitudes regarding interviews about injuries to their children *Injury Prevention* 6 51-55

Scottish Building Standards Agency (2005) *The Scottish Building Standards: technical handbook: domestic* SBSA Livingston

Sellick K Russell S Beckmann J (1983) Primary nursing: an evaluation of its effects on patients' perceptions of care and staff satisfaction *International Journal of Nursing Studies* 20(4) 265-273.

- Shields L (2001) A review of the literature from developed and developing countries relating to the effects of hospitalisation on children and parents *International Nursing Review* 48 29-37
- Shields L Kristensson-Hallstrom I O'Callaghan M (2003a) An examination of the needs of parents of hospitalised children: comparing parents' and staff's perceptions *Scandinavian Journal of Caring Sciences* 17 176-184
- Shields L Kristensson-Hallstrom I Kristjansdottir G Hunter J (2003b) Who owns the child in hospital? A preliminary discussion *Journal of Advanced Nursing* 41(3) 213-222
- Shields L Pratt J Hunter J (2006) Family centred care: a review of qualitative studies *Journal of Clinical Nursing* 15 1317-1323
- Sidebotham P (2001) Culture, stress and the parent-child relationship: a qualitative study of parent's perception of parenting *Child: Care Health and Development* 27 (6) 469-485
- Simons J Franck L Roberson E (2001) Parent involvement in children's pain care: views of parents and nurses *Journal of Advanced Nursing* 36(4) 591-599
- Smith L Bassett C (1996) Introducing change to the post-anaesthetic care unit *Nursing Standard* 11(9) 36-38
- Steinmetz D Tabenkin H 2001 The 'difficult patient' as perceived by family physicians *Family Practice* 5 495-500
- Steven A (1999) Named Nursing: in whose best interest? *Journal of Advanced Nursing* 29(2) 341-347
- St John D Pai L Belfer M Mulliken J (2003) Effects of a child with a craniofacial anomaly on stability of the parental relationship *Journal of Craniofacial Surgery* 14(5) 704-708
- Stoddard F Saxe G Ronfeldt H Drake J Burns J Edgren C Sheridan R (2006) Acute Stress Symptoms in Young Children With Burns *Journal of the American Academy of Child & Adolescent Psychiatry*. 45(1) 87-93
- Stoddard FJ Saxe G (2001) Ten-year research review of physical injuries *Journal of the American Academy of Child and Adolescent Psychiatry* 40 (10) 1128-1145
- Svavarsdottir E Rayens M (2005) Hardiness in families of young children with asthma *Journal of Advanced Nursing* 50 (4) 381-390

- Tak Y McCubbin M (2002) Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease *Journal of Advanced Nursing* 39(2) 190-198
- Teti D Hess C O'Connell M (2005) Parental perceptions of infant vulnerability in a pre-term sample: prediction from maternal adaptation to parenthood during the neonatal period *Development and Behavioral Pediatrics* 26(4) 284-291
- Thompson R Boyle D Teel C Wamback K Cramer A (1999) A qualitative analysis of family member needs and concerns in the population of patients with burns *Journal of Burn Care and Rehabilitation* 20 487-496
- Thompson R Edwards P Jarvis S Avery A Towner E Walsh S (1998) Childhood Accidents: is it time to prescribe safety equipment? *Community Practitioner* 71 138-141
- Thorne S Kirkham S MacDonald-Eames J (1997) Interpretive Description: a noncategorical qualitative alternative for developing nursing knowledge *Research in Nursing and Health* 20 169-177
- Topping A (2006) The Quantitative-Qualitative Continuum IN Gerrish K Lacey A (ed) *The Research Process in Nursing* Blackwell London
- Towner E Dowswell T (2002) Community-based childhood injury prevention interventions: what works? *Health Promotion International* 17(3) 273-284
- Van L Sicotte K Lassiter R Jablonski K Crean D Jeng J Jordan M (2004) Digital photography: enhancing communication between burn therapists and nurses *Journal of Burn Care and Rehabilitation* 25 54-60
- Vladutiu C Nansel T Weaver N Jacobsen H Kreuter M (2006) Differential strength of association of child injury prevention attitudes and beliefs on practices: a case for audience segmentation *Injury Prevention* 12 35-40
- Warner J (2006) *Perfect Madness – Motherhood in the age of anxiety* Vermilion London
- Warschausky S Kay J Buchman S Halberg A Berger M (2002) Health-related quality of life in children with craniofacial abnormalities *Plastic and Reconstructive Surgery* (110) 2 409-414
- Watkins P Cook EL May SR Still J Luterman A Purvis RJ (1996) Postburn psychologic adaptation of family members of patients with burns *Journal of Burn Care and Rehabilitation* 17 78-92
- Wilson H (2001) Power and Partnership; a critical analysis of the surveillance discourses of child health nurses *Journal of Advanced Nursing* 36(2) 294-301

Wimpenny P Gass J (2000) Interviewing in phenomenology and grounded theory: is there a difference? *Journal of Advanced Nursing* 31(6) 1485-1492

APPENDIX 1
SUMMARY OF PARTICIPANTS

Interview number	Age of child when injured	Present at interview	Pseudonym of child
1	3	Mother 1 Father 1	Lewis
2	2	Mother 2 Father(John)not present	Ryan
3	1	Mother 3 Father 3 (Scott)	Chloe
4	18 months	Mother 4	Adam
5	2	Mother 5 (Heather) Grandmother 5	Rachel
6	3	Mother 6 Father(Craig)not present	Jack
7	2	Mother 7	James
8	4	Mother 8	Matthew
9	9 months	Mother 9 Father 9 (John)	Philip

APPENDIX 2
HEALTH VISITOR LETTER

Dear Colleague,

I am writing to request your help in a research project I am undertaking as part of the Accident Prevention Safety in the Home project, and supervised by the University of Edinburgh. The research project has received ethical and management approval.

The aim of the research is to examine the effect of burn injury on the family, and also to discover how health professionals can best support these families.

I would like to interview families who meet the following inclusion criteria:

1. Their child has been burn injured while under the age of five
2. The injury required treatment at {specialist hospital}
3. The injury occurred not less than six months but not more than three years ago.

If you have any families on your caseload meeting these criteria, I would be very grateful if you would discuss the project with them, and if they agree pass their contact details to me using the form provided or by phone.

I will then contact them by post with further details of the research project. It is planned to interview participants in their home at a time convenient to them. Data will be gathered by means of a tape-recorded semi-structured interview. The results will be collated but it will not be possible for individuals to be identified from the results.

If you would like further details of the study, please do not hesitate to contact me on the above phone number.

Yours sincerely,

Helen Yewdall
Health Visitor/ Project Coordinator

APPENDIX 3
PARENT LETTER

Dear

I have been informed by your health visitor ----- that you might be willing to consider being involved in research I am undertaking as part of a degree course at Edinburgh University.

At present, I am coordinating a home safety project for ***** Healthcare NHS Trust, and part of that project is to find out how we can help to improve the care of families following an accident.

We know from the research that has already been done that a burn or scald injury is one of the most traumatic experiences that a family is likely to have, therefore I would like to find out your views and opinions on the healthcare that you received.

If you agreed to take part, I would come to your home to discuss with you your experiences at the time and how you feel the accident has affected you and your child since. The interview would be tape recorded so I am able to recall exactly what has been said.

The information that you provide will be confidential, and I will not pass on anything that is said to the health professionals involved in the care of your family.

The facts and opinions that are gathered from all the families involved will be recorded as part of the project, however it will not be possible for individual families to be identified from these results.

I will be in touch again in approximately one week, however if you have any questions or would like to discuss anything further, please do not hesitate to contact me on the above number.

Yours sincerely,

Helen Yewdall
Health Visitor/ Project Coordinator

APPENDIX 4
PARENT INFORMATION SHEET

A STUDY EXAMINING THE IMMEDIATE AND LONG-TERM HEALTHCARE EXPERIENCE OF PARENTS FOLLOWING THE BURN OR SCALD OF THEIR CHILD, AND THE EFFECT OF THE INJURY ON THE FAMILY.

We know from the research that has already been done that a burn or scald injury is one of the most traumatic experiences that a family is likely to have. I would like to talk to you about your feelings about the accident, and find out your views and opinions on the healthcare that you received.

If you agreed to take part, I would come to your home at a time to suit you to discuss with you your experiences at the time and how you feel the accident has affected you and your child since. The visit should take no longer than an hour, but the interview can be broken off at any time for whatever reason. The interview would be tape recorded, if you are willing and kept securely. At the end of the study, all of the tapes will be erased.

You are under no obligation to take part in this study and may withdraw at any time without giving a reason, without it affecting your care either now or in the future.

All the information that you give me will be completely confidential, and you will not be able to be identified in any reports. I will not pass on any information that you give to the health professionals involved in the care of your family, unless you wish me to do so.

If you would like to talk more about this study before deciding whether to take part, you can contact me at the number on your letter. If you want to talk to an independent person about the study who is not involved in the research then you can contact *****Health Visitor at ***** Health Centre on *****

APPENDIX 5
CONSENT FORM

CONSENT FORM

RESEARCH PROJECT: A STUDY EXAMINING THE IMMEDIATE AND LONG-TERM HEALTHCARE EXPERIENCE OF PARENTS FOLLOWING THE BURN OR SCALD OF THEIR CHILD, AND THE EFFECT OF THE INJURY ON THE FAMILY.

Name of Researcher: **Helen Yewdall**

Name of Participant:

I consent to take part in this research project.

I understand that the research is designed to add to medical knowledge and will not be of direct benefit to me.

I have read the information sheet about the study and I have had time to think about it.

I have had the study explained to me by Helen Yewdall.

I have been told that I can withdraw from the study at any time without giving a reason and without it affecting the care of my family in the future.

I have been given a copy of this Consent Form.

Signed

Date

I can confirm that I have explained to the participant the nature of the study, and have given adequate time to answer any questions concerning it.

Signed

Date

APPENDIX 6
GP INFORMATION LETTER

Dear Doctor,

Your patient ----- has agreed to take part in a qualitative research study I am undertaking as for a post-graduate degree at Edinburgh University, and also as part of the Trust's current Accident Prevention 'Safety in the Home' project.

I will be looking at the healthcare experience of parents following the burn or scald of their child, and how this has affected the relationships within the family. Data will be gathered by means of a tape-recorded semi-structured interview. The results will be collated but it will not be possible for individuals to be identified from the results.

Your patient has indicated their willingness for you to be informed of their participation, if you feel that it would not be in their best interests to take part in the study I would be grateful if you could contact me as soon as possible to indicate your views.

Yours sincerely,

Helen Yewdall
Health Visitor/ Project Coordinator

APPENDIX 7
INTERVIEW SCHEDULE

1. Demographic data: ages of parents and children, family composition,
2. When the injury occurred, and the age of the child. The family situation around that time.
3. How the accident happened and who was caring for the child at the time of the accident.
4. The nature of the injury sustained.
5. What happened immediately following the accident, details regarding hospital treatment, how the parents were dealt with and their feelings surrounding this.
6. Issues surrounding longer term care, whether the family was visited by a community children's nurse for ongoing treatment, and if their health visitor visited the family.
7. How the family felt about professional involvement long-term and if they felt this was effective. Their opinions on the attitude of healthcare professionals and if this could be improved for other families.
8. The reaction of the extended family and friends to the accident.

9. How the parents feel their relationship with the child has changed as a result of the accident, and whether it has changed their parenting style.
10. The parent's opinion on safety education received before the accident, and how their safety behaviours have changed as a result of the injury.
11. The impact that the accident has had on the family, and what the parents feel has been the long-term effect on their mental health.

APPENDIX 8
ETHICAL APPROVAL LETTERS

Our ref: BWM/KCM

24 August 2001

Mrs Helen Yewdall



- Cardiac Rehabilitation
- General Services
- Ophthalmology

Dear Mrs Yewdall,

RESEARCH PROTOCOL LREC/2000/1/19 - A QUALITATIVE STUDY EXAMINING THE IMMEDIATE AND LONG TERM HEALTHCARE EXPERIENCE OF PARENTS FOLLOWING THE BURN OR SCALD OF THEIR CHILD, AND THE EFFECT OF THE INJURY ON THE FAMILY

On behalf of ~~the NHS Trust~~ NHS Trust I am happy to grant management approval for the above study. This approval is granted subject also to ethical approval having been granted.



Yours sincerely,

Dr Brian Montgomery
Medical Director

c.c. Ms Annette Harris, Secretary, Anaesthetics/Dentistry/GP, Research Ethics Sub-Committee, Health
Ms Maggie Hughes, R & D Nurse, Redesign Office, Napier



Medical Director's Office
Tel: 422835
Fax: 461005
E-mail: brian.montgomery@nhs.uk
PA: Kay Morrison



OUR REF: LREC/2001/1/19

YOUR REF

PLEASE QUOTE THE ABOVE REFERENCE ON ALL CORRESPONDENCE

Mrs Helen Yewdall
Community Nursing Administration

24 September 2001

Dear Mrs Yewdall,

A qualitative study examining the immediate and long term healthcare experience of parents following the burn or scald of their child, and the effect of the injury on the family

Thank you for submitting the amendments or additional information requested by the Sub-Committee for the above protocol. The Chairman of the Anaesthetics/Dentistry/General Practice Research Ethics Sub-Committee has now agreed to confirm the Sub-Committee's ethical approval under its delegated authority.

Under the terms of the Scottish Office Home and Health Department Guidelines on Local Research Ethics Committees this decision has been notified to the NHS body under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility of deciding whether or not the research should go ahead taking account of the advice of the Research Ethics Sub-Committee and from whom you must obtain management approval before any work on the study can proceed.

Yours sincerely

ANNETTE HARRIS

Administrator

Anaesthetics/Dentistry/General Practice Research Ethics Sub-Committee

LOTHIAN HEALTH BOARD

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